

SLEEP PROBLEMS IN CHILDREN WITH AN INTELLECTUAL DISABILITY:
THE ROLE OF CHILD AND PARENT FACTORS, AND TREATMENT
EFFICACY USING THE SIGNPOSTS PROGRAM

A thesis submitted in partial fulfilment of requirements for
the degree of Doctor of Psychology

Anthony Robinson
(B.App Sci., Grad. Dip. Psych)

School of Health Sciences

Division of Psychology

RMIT University

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DECLARATION

I certify that except where due acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of the thesis is the result of work which has been carried out since the official commencement date of the approved research program; and, any editorial work, paid or unpaid, carried out by a third party is acknowledged.

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DISSEMINATION DETAILS

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Note that this publication includes two studies (Study 1 and Study 2). Study 1 was not conducted as part of this thesis. Throughout this thesis any reference that is made to this publication relates to Study 1 only.

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TABLE OF CONTENTS

SLEEP PROBLEMS IN CHILDREN WITH AN INTELLECTUAL DISABILITY: THE ROLE OF CHILD AND PARENT FACTORS, AND TREATMENT EFFICACY USING THE SIGNPOSTS PROGRAM	i
DECLARATION	ii
ACKNOWLEDGEMENTS	iii
DISSEMINATION DETAILS	iv
TABLE OF CONTENTS	v
LIST OF TABLES	xiii
LIST OF FIGURES	xv
ABSTRACT	1
1.1 Functions of Sleep	4
1.2 Stages of Sleep	5
1.3 Sleep in Children	7
1.4 The Biology and Regulation of Sleep	9
1.5 Sleep Disorders and Sleep Problems	11
1.6 Common Sleep Problems in Children	13
1.7 Assessment of Childhood Sleep Problems	16
1.8 Prevalence of Sleep Problems in TD Children	18
1.8.1 Sleep Problems in Early Childhood	18
1.8.2 Sleep Problems in Early to Middle Childhood	20
1.8.3 Sleep Problems During Adolescence	21
1.9 Prevalence of Sleep Problems in Children with an ID	22
1.9.1 Comparing Children with an ID to TD Children	22
1.9.2 Sleep Problem Variability in Children with an ID	23

1.10 Aetiology of Sleep Problems in TD Children and Children with an ID	26
1.11 Duration of Sleep Problems	29
1.12 Concluding Comments.....	30
CHAPTER 2. FACTORS ASSOCIATED WITH SLEEP PROBLEMS	32
2.1 Sleep Problems and Related Child Factors	32
2.1.1 Infant Temperament.....	32
2.1.2 Sleep Problem Occurrence and Age	34
2.1.3 Medical Conditions and Medication Use.....	36
2.1.4 Adaptive and Daytime Behaviour.....	40
2.1.5 The Role of Severity of Intellectual Disability for Sleep Problems in Children with an ID.....	44
2.2 Parent Factors Associated with Children's Sleep Problems	45
2.2.1 Perinatal Factors.....	46
2.2.2 Maternal Attachment.....	47
2.2.3 Maternal stress and depression	48
2.2.4 Personality.....	50
2.2.4.1 Eysenck's factor theory.....	51
2.2.4.2 Rotter's social learning theory.	53
2.2.5 Perceived control.....	56
2.3 Quine's longitudinal Sleep Study	57
2.4 Concluding Comments.....	58
CHAPTER THREE. TREATMENT OF SLEEP PROBLEMS IN TD CHILDREN AND CHILDREN WITH AN ID	60
3.1 Pharmacological Treatment	60
3.1.1 Research of Pharmacological Treatment for Sleep Problems in Children	62

3.1.2 Melatonin	65
3.2 Circadian Altering Strategies	68
3.2.1 Light Therapy.....	69
3.2.2 Chronotherapy.....	70
3.3 Behavioural Interventions	71
3.3.1 Positive bedtime routines	72
3.3.2 Systematic Ignoring	72
3.3.3 Graduated Ignoring	73
3.3.4 Ignoring with Minimal Check.....	74
3.3.5 Ignoring with Parental Presence.....	74
3.3.6 Scheduled Awakenings	74
3.3.7 Sleep Scheduling.....	75
3.3.8 Faded Bedtime	75
3.3.9 Prevention Through Parent Education	76
3.4 Studies of behavioural intervention efficacy.....	76
3.4.1 Group Designs.....	77
3.4.2 Single case designs.....	85
3.4.3 Conclusions Regarding Behavioural Interventions.....	88
3.5 Generalisation of Behavioural Strategies.....	89
3.6 Effect of Sleep Intervention on Parents	92
3.7 Barriers to Obtaining Appropriate Sleep Intervention	93
3.8 Conclusions	95
CHAPTER 4. STUDY 1: PARENT PERCEPTIONS OF SLEEP PROBLEMS AND TREATMENT EFFECTIVENESS IN CHILDREN WITH AN ID.....	97
4.1 Study Rationale, Aims, and Hypotheses	97

4.2 Method	98
4.2.1 Participants	98
4.2.2 Materials	99
4.2.3 Procedure	101
4.2.4 Data Analysis	101
4.3 Results	102
4.3.1 Background Information	102
4.3.2 Sleep Characteristics	104
4.3.2.1 Average Sleep per Night	105
4.3.2.2 Medical Conditions, Medication use, and Sleep	105
4.3.2.3 Sleep Problems and age	106
4.3.2.4 Types of Sleep Problems and Parent Perception	107
4.3.2.5 Sleep Problems Across Disability Types	108
4.3.2.6 Parents who Rated Their Child as Displaying Problematic Sleep Behaviour but did not Perceive Their Child to Have a Sleep Problem.....	108
4.3.2.7 Predicting Parental Perception of a Sleep Problem	110
4.3.3 Treatment	112
4.4 Discussion	113
4.4.1 Prevalence Rates and Parental Perceptions of Sleep Problems	114
4.4.2 Treatment	116
4.4.3 Medical Conditions and Medication Use	117
4.4.4 Limitations of Study	118
4.4.5 Summary and Conclusions	119
CHAPTER 5. STUDY 2: FACTORS AFFECTING PARENTAL PERCEPTION OF SLEEP PROBLEMS IN CHILDREN WITH AN ID	121

5.1 Study Rationale, Aims, and Hypotheses	121
5.2 Method	122
5.2.1 Participants	122
5.2.2 Materials	123
5.2.2.1 Demographic Details	123
5.2.2.2 Sleep Measure	123
5.2.2.3 Child Behaviour Measure	125
5.2.2.4 Measure of Adaptive Behaviour	126
5.2.2.5 Personality Measure	127
5.2.2.6 Parent Competence Measure	127
5.2.2.7 Measure of Parent Stress	128
5.2.2.8 Measure of Locus of Control	128
5.2.2.9 Perceived Control over the Child's Sleep and Daytime Behaviour	129
5.2.3 Procedure	130
5.2.4 Data Analysis	130
5.3 Results	132
5.3.1 Child Demographics	132
5.3.2 Parent/Primary Carer Demographics	134
5.3.3 Parent Perception of a Sleep Problem	134
5.3.4 Child Characteristics Across Sleep Groups	136
5.3.5 BEDS Data for the Sleep Problem Group and the No Sleep Problem Group	138
5.3.6 Allocating Children to the Sleep Problem Group where Parents/Carers do not recognise that a Sleep Problem Exists	140
5.3.7 Demographics of the Three Sleep Groups	140

5.3.8 Average Sleep Length Across the Three Sleep Groups	141
5.3.9 Child Daytime Behaviour	142
5.3.10 Child Adaptive Behaviour	142
5.3.11 Parent Perceived Control Over Sleep and Daytime Behaviour	144
5.3.12 Parent Personality.....	145
5.3.13 Parental Stress	145
5.3.14 Locus of Control	145
5.3.15 Parental Satisfaction and Efficacy	146
5.3.16 Predicting Sleep Group Membership	147
5.3.17 Sleep Group Analysis of Child and Parent Variables Among Disability Types	148
5.4 Discussion	150
5.4.1 Problematic Daytime Behaviour and Adaptive Behaviour of the Child.	151
5.4.2 Parent Factors.....	151
5.4.3 Change of Sleep Problem Perception over time	153
5.4.4 Diagnosis Specific Results.....	154
5.4.5 Study Limitations	155
5.4.6 Summary and Conclusions.....	156
CHAPTER 6. STUDY 3: A GENERAL PARENT TRAINING PROGRAM FOR THE BEHAVIOIURAL MANAGEMENT OF SLEEP PROBLEMS FOR CHILDREN WITH AN ID	
6.1 Study Rationale, Aims, and Hypotheses	159
6.2 Method	161
6.2.1 Participants.....	161
6.2.2 Materials.....	163

6.2.2.1 Demographic Information.....	163
6.2.2.2 Sleep Information.....	163
6.2.2.3 Child Behaviour Information.....	166
6.2.2.4 Parent Information	166
6.2.2.5 Social Validity.....	166
6.2.2.6 The Signposts program	167
6.2.3 Procedure.....	169
6.2.3.1 Recruitment.....	169
6.2.3.2 Intervention Program	171
6.2.3.3 Follow-up	174
6.2.4 Study Design	175
6.2.5 Sleep Problem Descriptions	176
6.2.5.1 Participant 1	176
6.2.5.2 Participant 2	176
6.2.5.3 Participant 3	177
6.2.5.4 Participant 4	178
6.2.5.5 Participant 5	178
6.2.6 Data Analysis	179
6.3 Results.....	181
6.3.1 Participant Attrition.....	181
6.3.2 Child Sleep Results	181
6.3.2.1 BEDS Data	181
6.3.2.2 GAS for Target Sleep Behaviour	184
6.3.2.3 Child Sleep Diaries	184
6.3.2.4 Subjective Ratings of Sleep Change	187

6.3.3 Results for Child Daytime Behaviour	195
6.3.3.1 DBC Results.....	195
6.3.3.2 GAS for Target Daytime Behaviour	195
6.3.4 Results for Parent Factors	197
6.3.4.1 Results from Parent Questionnaires	197
6.3.4.2 Results from Parent Sleep Diaries	199
6.3.4.3 Parent Evaluation of Intervention Program.....	201
6.4 Discussion	205
6.4.1 Child Sleep Outcomes.....	206
6.4.2 Child Daytime Behaviour Outcomes	207
6.4.3 Parent Outcomes	208
6.4.4 Comparison of Results Across Participants	208
6.4.5 Study Limitations	209
6.4.6 Conclusion and Future Directions.....	211
CHAPTER 7. GENERAL DISCUSSION	213
7.1 Summary of Findings	213
7.1.1 Parent Perceptions of sleep problems in children with an ID	213
7.1.2 Treatment of Sleep Problems in Children with an ID.....	219
7.2 Methodological considerations	226
7.3 Implications for future research	228
7.4 Conclusion	230
REFERENCE LIST	232
REFERENCE LIST	232

LIST OF TABLES

Table 4.1. The Types and Frequencies of Medical Conditions Associated with ID in Study 1 Participants	103
Table 4.2. The Types and Frequencies of Other Diagnosed Medical Conditions for Study 1 Participants	104
Table 4.3. Types of Child Sleep Disturbance and Frequency as Reported by Parents	105
Table 4.4. Frequencies and Percentages of Medical Conditions, Medication use, and SleepRatings Across Disability Groups	109
Table 4.5. Types of Sleep Difficulties and Frequencies (%) forParental Perception of a Child Sleep Problem and Parental Sleep Disruption Due to the Child's Sleep	111
Table 5.1. The Types and Frequencies of Diagnoses Associated with ID.....	133
Table 5.2. The Types and Frequencies of Other Medical Conditions	134
Table 5.3. Parent / Primary Carer Demographics	135
Table 5.4. Participants who Changed Their Mind Between Study 1 and Study 2 Regarding Whether Their Child had a Sleep Problem or not and Their Explanations.	137
Table 5.5. Descriptive Statistics for Gender, Diagnosis, Educational Placement, Medical Conditions, and Medication Use Across Groups.	138
Table 5.6. Differences Between the Sleep Problem Group and No Sleep Problem Group on Sleep Characteristics as Measured by the BEDS: Mean Scores, Standard Deviations, and Independent Sample t-Test Results.....	139
Table 5.7. Frequencies and Percentages of Child Characteristics Across Sleep Groups	141

Table 5.8. Comparisons of Child Daytime Behaviour across the Three Sleep Groups	143
Table 5.9. Comparisons of Child Adaptive Behaviour across the Three Sleep Groups	143
Table 5.10. Perceived Control Across Sleep Groups Compared with Results from a Previous Study (medians, and 10 th -90 th percentiles).	144
Table 5.11. Comparisons of Parent Personality Traits Across the Sleep Groups...	145
Table 5.12. Comparisons of Parental Stress Across the Three Sleep Groups.....	146
Table 5.13. Comparisons of Locus of Control Across the Three Sleep Groups.....	146
Table 5.14. Comparisons of Parental Sense of Competence Across Sleep Groups.	147
Table 5.15. Descriptive Statistics for Gender, Diagnosis, Educational Placement, Medical Conditions, and Medication Use Across Groups.	149
Table 6.1 Demographic Information of Children in Study 3.	162
Table 6.2 Demographic Information of Parents in Study 3.	163
Table 6.3. Individual BEDS Scores at each Phase Compared to Control Scores	183
Table 6.4. Participant GAS Success for Sleep Problem Behaviour.....	185
Table 6.5. Ratings for Sleep Variables with Baseline Compared to end of Intervention and Follow-up.....	186
Table 6.6. Individual DBC Scores and Percentile Rank at Baseline and Follow-up	196
Table 6.7. Participant GAS Success for Compliance to Parent Request	197
Table 6.8. Individual Scores for Parent Measures at each Phase.....	198
Table 6.9. Ratings for Parent Sleep Variables with Baseline Compared to end of Intervention and Follow-up.....	200

LIST OF FIGURES

Figure 6.1 The amount of time taken to fall asleep for each child, during baseline, intervention, and follow-up	187
Figure 6.2 The number of times each child co-slept per week, during baseline, intervention, and follow-up	188
Figure 6.3 Number of times each child woke at night, during baseline, intervention, and follow-up	189
Figure 6.4 The average time each child spent awake with each night waking episode during baseline, intervention, and follow-up	190
Figure 6.5 The average weekly sleep duration of each child during baseline, intervention, and follow-up	191
Figure 6.6 Average weekly ratings of sleep quality during baseline, intervention, and follow-up	192
Figure 6.7 The average total sleep duration for each parent during baseline, intervention, and follow-up	201
Figure 6.8 Number of times each parent woke at night during baseline, intervention and follow-up	202
Figure 6.9 Weekly average ratings of parental sleep quality during baseline, intervention and follow-up	203

LIST OF APPENDICES

Appendix A. Plain Language Statement	247
Appendix B. Sleep Questionnaire	249
Appendix C. RMIT Human Research Ethics Committee Approval for Study 1 and 2	252
Appendix D. Department of Education (Victoria) Approval for Study 1 and 2.....	254
Appendix E. Current Medications Taken by Participants. Class, Purpose for use and Sleep Side Effects	257
Appendix F. Treatments Tried to Alleviate Sleep Problem.....	261
Appendix G. Demographic Information Sheet	263
Appendix H. Plain Language Statement Study 2.....	265
Appendix I. Consent Form Study 2.....	267
Appendix J. Current Medications Taken by Participants. Class, Purpose for use and Sleep Side Effects	270
Appendix K. Reasons Given by Parents to Explain why Their Child has/does not have a Sleep Problem	274
Appendix L. Children allocated to the Unrecognised Sleep Problem Group, BEDS factors above the cut-off, parental reasons why the parent/carer doesn't think the child has a sleep problem.	280
Appendix M. Allocation of Parents/Carers From the No Sleep Problem Group to the Unrecognised Sleep Problem Group.....	282
Appendix N. Parent Sleep Diary	286
Appendix O. RMIT Human Research Ethics Committee Approval for Study 3.....	288
Appendix P. Plain Language Statement for Study 3.....	290

Appendix Q. Consent Form for Study 3	293
Appendix R. Outline of Signposts Sleep Groups.....	296

ABSTRACT

Research indicates that night settling, night waking, co-sleeping, and early waking are the most common sleep problems reported by parents. These sleep problems are particularly high for parents who have a child with an ID and are associated with difficult child daytime behaviour, and high levels of parent stress. This issue is further complicated by the fact that parents often do not seek help for the problem, perhaps believing that it is due to the child's disability and cannot be treated. Also of concern is the fact that research has shown some parents do not recognise/perceive their child's sleep to be problematic. While treatment is possible, often those parents who do seek help are provided with incorrect advice. Behavioural intervention is an effective form of treatment, however, a number of studies that have reported on the successful treatment of sleep problems in children with an ID have not found an expected associated improvement in child daytime behaviour and parent stress.

The current research considered parent report of sleep problems in children with an ID. Of specific interest were parents who reported child sleep issues/disturbances but who did not consider their child to have a sleep problem. Also of interest was the use of a general parent-training program to treat both the sleep and behaviour problems in children with an ID.

Study 1 examined parent perceptions regarding sleep in children with an ID. Parents reported child sleep behaviours and answered whether or not they thought the sleep behaviours constituted a sleep problem. Parents who reported a child sleep problem also provided information on the types of sleep treatment tried and gave ratings regarding their perceived effectiveness. In total, 243 questionnaires were completed by parents of children with a range of disabilities aged between 3.1 to 18.7 years. While 62% of parents rated their child as displaying problematic night

settling, night waking, early waking, or other disturbing sleep behaviours, only 27% of parents considered their child to have a sleep problem. A higher number of parents (75%) than expected had tried at least one type of intervention, although it was not possible to discern 'self help' treatments from 'professionally sought' treatments. Average parent ratings of treatment effectiveness were poor for all four treatment groups (behavioural, pharmacological, herbal, and other). These findings confirmed previous reports that some parents describe child sleep disturbance but don't believe that their child has a sleep problem (Bartlett, et al. 1985; Wiggs & Stores, 1996a) and were the basis of further examination in Study 2.

Study 2 investigated child and parent factors associated with parent perception of sleep problems in children with an ID. Seventy-six parents from Study 1 completed measures in relation to child adaptive and daytime behaviour, parent stress, locus of control, personality (extraversion, neuroticism, and psychoticism), parenting competence, and perceived control over the child's sleep and daytime behaviour. Based on parent report on a sleep measure and parent response to the question 'do you think your child has a sleep problem' parents were allocated into one of three sleep groups: Parents who recognised that their child had a sleep problem (RSP, $N=20$), parents whose child did not have a sleep problem (NSP, $N=35$), and parents who did not recognise their child to have a sleep problem (USP, $N=21$). The results revealed differences between parents who do (RSP) and parents who do not (USP) recognise their child's sleep problem. These differences were related to amount of child sleep (as reported by parents) and parent perceived control over the child's sleep and daytime behaviour. In contrast to previous research (Wiggs & Stores, 1998b), a difference across the three groups on parent stress, locus

of control, and child behaviour were not reported, indicating that perceived control exerts a direct influence on parent recognition of a sleep problem.

Study 3 examined the efficacy of a general parent-training (behaviour management) program, with sleep used as the training exemplar, for the treatment of sleep problems in children with an ID. Of the 20 parents in the RSP group in Study 2, five agreed to take part in Study 3 and three completed the intervention. The effect of the intervention on (a) a targeted sleep problem, (b) a targeted behaviour problem, (c) other sleep and daytime behaviours, (d) parent stress, (e) parent sleep, (f) parent sense of competence, and (g) parent perceived control over the child's sleep and daytime behaviour were examined. All parents reported an improvement in their child's target sleep behaviour, and at follow-up all of the parents no longer considered their child to have a sleep problem. One parent reported a decrease in stress and an increase in measures of perceived control, and parenting competence, while two parents showed minimal to no improvement on child and parent outcomes. The hypotheses from Study 3 were only partially supported, however, they indicate that a parent-training program, with sleep used as an exemplar, could be effective in resolving sleep and behaviour problems of children with an ID.

This thesis serves to increase the understanding regarding sleep problems in children with an ID by highlighting the importance of parent recognition/perception of a sleep problem. The limitations and significance of these studies in relation to future research and practical implications are discussed.

CHAPTER 1. PREVALENCE, DURATION, AND AETIOLOGY OF SLEEP PROBLEMS IN CHILDREN

Sleep problems in children are a common occurrence, and often have a harmful effect on the functioning of the child and the child's family (Armstrong, Quinn, & Dadds, 1994; Stores, 1996). Furthermore, of all the childhood behavioural disturbances, sleep problems remain the most persistent (Mindell, 1997). This chapter explains the structure and development of sleep in children, and considers the different types of childhood sleep problems. An explanation of the nature and occurrence of the most common sleep problems in typically developing (TD) children and children with an intellectual disability (ID) is then provided.

1.1 Functions of Sleep

Sleep is defined as “a reversible behavioural state of perceptual disengagement from and unresponsiveness to the environment” (Carskadon & Dement, 2005, p.13). Many theories and much debate have circulated concerning the purpose of sleep. Common observations and research findings have yielded several prominent theories of sleep function including energy conservation, memory consolidation, adaptive processes, brain growth, discharge of emotions, and the restorative theories of sleep (Hirshkowitz, Moore, & Minhoto, 1997). While many sleep hypotheses have been suggested, no single model has provided an adequate account of the purpose of sleep, thus the functional role of sleep is still unknown (Frank, 2006). However, sleep deprivation studies have been used to examine the sleep phenomenon. Over time, sleep deprivation in humans can have a number of

negative side effects that may include decreased alertness, mood changes such as irritability and fatigue, short-term memory alterations, and decreased motivation. Furthermore, illusions, hallucinations, visual misperceptions, and paranoid ideation have been observed in sleep-deprived individuals (Culebras, 1996). While the precise purpose of sleep remains ambiguous, research has shown that the sleep process consists of two physiologically distinct states.

1.2 Stages of Sleep

Sleep is divided into two main states: rapid eye movement sleep (REM) and non-REM sleep (NREM). During sleep, the brain moves through these two states in a cyclical fashion (Carskadon & Dement, 2005). A basic polysomnogram is used to distinguish between the sleep states. It consists of three electrophysiological measures: the electroencephalogram (EEG) measures brain waves, the electromyogram evaluates muscle tone, and the electro-oculogram is concerned with eye movement (Dahl, 1995). EEG activity measures the frequency and amplitude of the brain waves. The frequency relates to the number of brain wave cycles per second, measured as hertz (Hz). The amplitude refers to the height of electrical activity that is generated, and is measured in microvolts (μV). EEG activity is divided into four categories based on frequency ranges: delta (0.5-3 Hz), theta (4-7 Hz), alpha (8-13 Hz), and beta (14-25 Hz) (Berry, Geyer, & Carney, 2005; Hirshkowitz et al., 1997).

NREM sleep consists of four stages that are associated with the depth of sleep. Stage 1 sleep, also known as drowsiness, is a light form of sleep that represents the transition from wakefulness to sleep (Durand, Mindell, Mapstone, & Gernert-Dott, 1998). It is characterised by low-voltage, mixed-frequency EEG

activity, as well as slow rolling eye movements, and a reduction in muscle tone (Culebras, 1996). A typical young adult spends approximately 2-5 % of sleep in Stage 1 (Hirshkowitz, Moore, Hamilton, Rando, & Karacan, 1992). Stage 1 sleep is followed by Stage 2 sleep. This is considered the first true sleep state and is characterised by sleep spindles and K complexes in the absence of significant slow wave activity (Hirshkowitz et al., 1997). Sleep spindles are EEG waveform bursts with a waxing and waning nature, while K complexes consist of a high-voltage (10-14 Hz) waveform that has an apparent upward and downward component. Between 45-55% of sleep is spent in Stage 2 for a typical young adult (Bae & Foldvary-Schaefer, 2005).

Stages 3 and 4 of NREM sleep are the deepest stages of the sleep process, whereby awakening is most difficult. They are defined by delta activity, and are commonly referred to as delta sleep or slow wave sleep (Stores, 2001b). After 15-30 minutes in Stage 2 sleep, the delta waves begin to appear. Stage 3 sleep is scored when 20-50% of the polysomnographic epoch (standard recording interval) is comprised of delta activity. Stage 4 of NREM sleep occurs when the slow wave activity occupies more than 50% of the epoch (Culebras, 1996). The typical young adult spends between 3-8% of sleep in Stage 3 and 10-15% of sleep in Stage 4 (Hirshkowitz et al., 1992). After 30-45 minutes of Stage 3 and Stage 4 NREM sleep, the sleep cycle reverses back to Stage 2. This is followed by a brief arousal that marks the onset of REM sleep and the end of the first cycle of sleep (Culebras, 1996).

In contrast to NREM sleep, REM sleep consists of an EEG pattern that is similar to that depicted in the awakened state (Stores, 2001b). The EEG during REM sleep is marked by low-voltage, mixed-frequency activity without the presence of

sleep spindles or K complexes (Culebras, 1996). REM sleep is associated with a marked reduction in muscle tone, rapid eye movements, and small facial movements. (Curzi-Dascalova & Challamel, 2000). Dreaming is closely associated with REM sleep. REM sleep is also known as “paradoxical sleep” because it contains a combination of light sleep (higher brain activity) and deep sleep (muscles become atonic) features (Dahl, 1995). Between 20-25% of sleep is spent in the REM stage (Hirshkowitz et al., 1992).

The sleep process continues through the above cycle four or five times a night, with an alternation of NREM and REM sleep stages occurring approximately every 90-120 minutes. Most delta sleep occurs in the first third of the night, and disappears after the second cycle, while most REM sleep occurs in the second half of the night, and increases as the night progresses (Carskadon & Dement, 2005; Culebras, 1996). Even though these cycles are common in everyone, there are pronounced differences across age in sleep organisation, type, and structure (Mindell, 1997).

1.3 Sleep in Children

While adults typically have one sleep period lasting approximately 8 hours, newborn infants have polyphasic sleep periods that result in up to seven sleeping and waking periods in the course of one day, totalling approximately 17 hours of sleep per day. Sleep in infants is classified as active or quiet. Active sleep is the equivalent of REM sleep in adults, while quiet sleep corresponds to NREM sleep in adults (Mindell, 1997). Active, or REM sleep is exhibited during sleep onset in infants, while this is considered abnormal in adults (Culebras, 1996; Hirshkowitz et al., 1997). Active sleep also accounts for 50% of sleep in very young infants compared

to 25% for adults. Furthermore, adult cycles are around 90 minutes long, whereas infant cycles are between 45-60 minutes (Berry et al., 2005; Mindell, 1997).

Quiet, or NREM sleep in very young infants is poorly developed, and the typical features of this phase such as sleep spindles, K complexes, and slow waves, are not present until the age of 3 months (Culebras, 1996). Also, quiet sleep accounts for less of the total sleep time in infants. After the age of 3 months, infant sleep begins to resemble the typical sleep pattern of adults. From this age onwards, REM sleep starts to decrease while NREM sleep increases. REM sleep no longer occurs during sleep onset as NREM becomes more dominant during the early phases of sleep (Sadeh, 2000).

By the age of 3-4 months, the majority of infants have developed a diurnal sleep-wake cycle that includes daytime naps, and by 6 months of age this pattern is further developed with infants sleeping longer at night and engaging in fewer daytime sleep periods (Mindell, 1997). At 24 months of age, toddlers sleep approximately 13 hours including one daytime nap, while at 4 years of age total sleep time reduces further to approximately 11 hours and daytime naps usually no longer occur (Ferber, 1985).

From preschool years up until pre-adolescence this sleep cycle remains stable with children gradually obtaining less sleep. The decrease in sleep duration is due to a reduction in REM sleep with the amount and percentage declining through childhood until adolescence. The amount of Stage 4 sleep also decreases throughout childhood and is accompanied by an increase in Stage 2 sleep (Ferber, 1985; Sadeh, 2000). The onset of adolescence leads to rapid changes in the sleep and wake patterns. Adolescence triggers a significant reduction in slow wave sleep and total sleep time also decreases dramatically to approximately 8 hours per night (Dahl,

1995; Ferber, 1985). There is a tendency to delay sleep onset and morning rise time, with many adolescents not obtaining enough sleep, and suffering from daytime sleepiness. This change in total sleep time is influenced by psychosocial demands as well as biological mechanisms (Sadeh, 2000). Teenagers, like adults, also exhibit variability in their sleep schedules, thus potentially upsetting the timing of the sleep-wake cycle.

1.4 The Biology and Regulation of Sleep

There are three processes involved in sleep regulation. An ultradian process occurs during sleep and is characterised by the alternation of REM and NREM sleep states. A homeostatic process regulates sleep-wake balance and acts to counter deviations from average sleep levels. Thus, the more an individual is deprived of sleep or of a specific sleep stage (such as REM sleep) the greater the drive to recover the sleep loss. The timing and propensity of sleep are also moderated by a circadian process that is independent of previous sleep and waking (Borbély & Achermann, 2005).

The sleep-wake cycle is a circadian rhythm (biological cycle) that is regulated by the suprachiasmatic nucleus of the hypothalamus and has an oscillatory period of approximately 24 hours (Hirshkowitz et al., 1997; Mistlberger & Rusak, 2005). Thus, the timing of sleep needs to be entrained to the 24-hour day-night cycle. This entrainment is achieved via the presence of external time cues or zeitgebers. The sleep rhythm is mainly entrained to the 24-hour cycle by light; however, cues such as hunger, temperature, physical activity, and social activities also play a role. Without access to the light-dark cycle or other such external cues, daily sleep onset would occur approximately every 25 hours instead of every 24 hours, hence causing

sleep onset to shift slightly later each day or free-run (Mistlberger & Rusak, 2005). In infants entrainment of sleep and wakefulness to the 24-hour cycle is evident at the age of 3 to 4 months. At 3 months of age the longest sleep period occurs during the night, while at 6 months the longest periods of sleep and wakefulness occur at fixed times (Curzi-Dascalova & Challamel, 2000).

While the hypothalamus plays an important role in sleep-wake cycle regulation, other brain regions are essential to the sleep-wake process. The following is intended as a brief overview of the anatomical and neuronal systems that are implicated in the transition from wakefulness to sleep and vice versa. Steriade and McCarley (2005) provide a comprehensive biological review of the sleep and waking states.

Wakefulness is maintained by neurons in the brainstem reticular formation that excite neurons in the posterior hypothalamus and the basal forebrain. This in turn activates the cerebral cortex, stimulating fast activity of the EEG. Neurotransmitters contained within the specific neuronal systems that maintain wakefulness include catecholamines, acetylcholine, histamine, orexin, and glutamate. Several peptides including substance P, vasoactive intestinal peptide, and neurotensin also enhance waking (Jones, 2005).

When sleep occurs there is a transfer from sympathetic to parasympathetic regulation, and wake-activation systems are dampened. Sleep inducing neurons are located in the lower brainstem reticular formation, solitary tract nucleus, anterior hypothalamus, and in the basal forebrain. Inhibition of the activating systems is due to GABA neurons that turn the fast, tonic discharge into a slow bursting discharge that is reflected as spindles and slow wave activity on the EEG (Jones, 2005).

Having an understanding of the physiology, stages, development, and timing of sleep is necessary in order to be able to properly evaluate and diagnose the various types of sleep problems and sleep disorders that exist (Dahl, 1995).

1.5 Sleep Disorders and Sleep Problems

Sleep disorders are defined as “conditions or circumstances, of a physical or psychological nature (or both combined), that cause a sleep disturbance or problem of one type or another” (Stores & Wiggs, 2001, *p.*16). Hence, for children a sleep problem is the sleep behaviour that occurs as a result of the sleep disorder, and causes concern typically to the child’s parents. There are three major types of sleep problem that may be caused by one of a number of sleep disorders: The first type of sleep problem involves difficulty initiating and maintaining sleep, while the second category is excessive daytime sleepiness, and the third type relates to disturbances in behaviour during the night (Mindell, 1997). The International Classification of Sleep Disorders Diagnostic and Coding Manual (ICSD: ASDA, 2001, 2005) lists over 80 types of sleep disorders. Sleep disorders are commonly divided into two main categories: the parasomnias and the dyssomnias. The ICSD also recognises two other categories of sleep disorder: Sleep disorders that are associated with mental, neurologic, or other medical disorders, and proposed sleep disorders that have not yet been accepted as definitive sleep disorders.

The parasomnias relate to behaviours that intrude upon the sleep process, and do not primarily result in complaints of insomnia or excessive sleepiness (ASDA, 2001). Rather, the behaviours are a manifestation of central nervous system arousal, particularly occurring through the motor and autonomic nervous system pathways (Anders & Eiben, 1997). The parasomnias are divided into four groups: arousal

disorders, sleep-wake transition disorders, parasomnias usually associated with REM sleep, and other parasomnias. Arousal disorders, such as sleepwalking and sleep terrors, are caused by impaired arousal from sleep. Sleep-wake transition disorders, such as sleep talking, occur in the transition from wakefulness to sleep or during the transition of sleep stages. Parasomnias usually associated with REM sleep, such as nightmares, are thought to be the result of REM sleep abnormality. Other parasomnias, such as sleep bruxism or sleep enuresis, are sleep disorders that cannot be classified in the above three categories (ASDA, 2001).

The dyssomnias contain sleep disorders that result in sleep problems regarding excessive sleepiness, or insomnia (difficulty initiating and/or maintaining sleep). The ICSD manual lists three groups of dyssomnias: Intrinsic sleep disorders, circadian rhythm sleep disorders, and extrinsic sleep disorders. Intrinsic sleep disorders, such as narcolepsy and obstructive sleep apnoea syndrome, are caused by pathology or abnormal sleep physiology arising from within the body. Circadian rhythm sleep disorders, such as shift work sleep disorder, have an underlying chronophysiological basis, and relate to the inappropriate timing of sleep within the 24-hour day. Extrinsic sleep disorders, such as adjustment sleep disorder, are caused by factors outside of the body. Withdrawal of the external factor results in amelioration of the sleep disorder (ASDA, 2001).

Just as the sleep process in infants and children differs greatly to that of adults, the nature, and occurrence of sleep problems in this population also varies from the typical array of sleep disturbances that are present in adults.

1.6 Common Sleep Problems in Children

For children, sleep problems are thought to exist when sleep behaviour causes a problem for the child, the child's family, or both (Ferber, 1985). In children, the most common types of sleep problems are night waking, closely followed by night settling difficulties (Durand et al., 1998). Sleeping in bed with parents (co-sleeping) and early morning waking also commonly occur. Co-sleeping, night settling, and night waking disturbances are usually classified as extrinsic dyssomnias resulting in problems initiating and maintaining sleep, and typically prevail during the preschool years (Anders & Eiben, 1997). In the ICSD manual (ASDA, 2001), night settling, night waking and/or co-sleeping difficulties in children are the essential features of limit-setting sleep disorder and sleep-onset association disorder.

Limit-setting sleep disorder involves delayed sleep onset through the child stalling or refusing to go to bed, and the parent/caretaker not enforcing appropriate bedtime limits. This sleep disorder may occur from late infancy through adolescence, however it is most common when the child is first moved into a bed. Sleep-onset association disorder is characterised by impaired sleep onset due to the absence of a certain set of conditions that induce sleep. Parents/caretakers are usually somehow involved in these sleep onset conditions. Thus, during typical nighttime wakings the child finds it difficult to return to sleep unless the original sleep onset conditions are reinstated. This leads to the child calling out or wandering into the parents' bedroom, and causes sleep loss for the parent/caretaker. Age of onset is typically any time from late infancy through to toddler years. There is generally no sleep pathology for the more usual night waking or night settling problems. When sleep occurs, it is normal (ASDA, 2001; Stores, 1996).

Other extrinsic dyssomnias occurring in childhood are nocturnal fears, and adjustment sleep disorder. Fear and anxiety at bedtime are the cause of settling, and waking problems in children who have nocturnal fears. Adjustment sleep disorder results in settling problems, daytime anxiety and sleepiness, or early waking that occurs in relation to acute stress, anxiety or environmental change (Quine, 2001).

Early morning waking, where the child is noisy and demanding can be frustrating for the entire family, making it one of the most difficult sleep problems (Ferber, 1985; Stores, 2001a). In the ICSD manual, early morning waking in children may be the result of an adjustment sleep disorder (as mentioned above), an environmental sleep disorder or an advanced sleep-phase syndrome. Environmental sleep disorder is an extrinsic dyssomnia whereby sleep disturbance occurs as a result of the presence of an environmental factor such as heat, cold, light, noise, etc. Removal of the factor consequently leads to a normal pattern of sleep and wakefulness. While this sleep disorder may occur at any age, elderly people too have an increased risk of developing the disorder. In advanced sleep phase syndrome the child's time of sleep onset is earlier than the social norm, and awakening occurs before 5 a.m. The child obtains the normal amount of sleep for their age, but their sleep episode is advanced so that they tire early in the evening and wake unusually early (ASDA, 2001).

Alternatively, early morning waking may occur in children who have an early morning nap. In this instance the final sleep cycle becomes separated from the rest of the child's sleep, and emerges later that morning in the form of a nap. Finally, some children may be naturally early wakers, and the morning is their best time of functioning (Ferber, 1985).

Two types of intrinsic dyssomnia that occur in childhood are narcolepsy and obstructive sleep apnoea syndrome. Unlike the extrinsic dyssomnias mentioned above, these disorders cause excessive daytime sleepiness. Narcolepsy is characterised by repeated episodes of naps or lapses into sleep. Its peak incidence is approximately 14 years of age and is associated with REM sleep phenomena such as cataplexy, sleep paralysis, and hypnagogic hallucinations (ASDA, 2001). Obstructive sleep apnoea syndrome relates to difficulty breathing during sleep as result of partial or complete obstruction of the airway. Such obstruction is typically associated with reduced blood oxygen levels and/or raised levels of carbon dioxide (Stores, 1996). This disorder can occur in children of any age, however, it tends to be more common in pre-school age children. Risk factors for this disorder include adenotonsillar hypertrophy, obesity, neuromuscular disease, and craniofacial anomalies (Schroeder, 2002).

Since parasomnias are an indication of central nervous system arousal, they are more common in children than in adults and are usually outgrown (Thiedke, 2001). Sleepwalking (somnambulism), sleeptalking (somniloquy), and night terrors most commonly occur in school-aged children and are all related to transitions from deep stages of NREM sleep to lighter stages of NREM sleep (Dahl, 1995). Sleep terrors are accompanied by screams, intense fear, confusion and disorientation upon awakening. Once the episodes are over, return to sleep is spontaneous and there is no recollection of the episode in the morning (Ward & Mason, 2002). Conversely, nightmares are terrifying dreams that occur later in the night during REM sleep, and are further characterised by a vivid recall of events upon awakening and difficulty returning to sleep (Stores, 1996). Sleep bruxism is a loud grinding of the teeth that occurs during sleep. Episodes last between 5-15 seconds and may lead to face pain

or headache (Quine, 2001). Nocturnal enuresis or bed-wetting after 5 years of age is one of the most prevalent and persistent sleep problems in children. While it tends to occur during the first half of the night, it can transpire at any stage of the sleep process (Stores, 1996; Thiedke, 2001).

Restless legs syndrome is a disorder of unknown neurological origin that is characterised by an irresistible urge to move the limbs while resting. Symptoms are worse in the evening while the individual is lying down with motor activity leading to temporary relief (Becker, 2007). Symptoms often first appear during childhood and may lead to insomnia and night wakings (Owens & Finn Davis, 2007).

Correct diagnosis of a sleep problem involves an accurate reporting of the sleep history (Stores & Wiggs, 2001). As parents or caregivers are usually the sole reporters of this history, the sleep problem being evaluated also considers the impact that the child's sleep behaviour is having on the parents (Culebras, 1996).

1.7 Assessment of Childhood Sleep Problems

A variety of methods are available for sleep problem assessment in children. In sleep research, questionnaires are often used to make clinical enquiries considering the nature of the current complaint, medical factors, the child's 24 hour sleep-wake schedule, the effect the sleep problem is having on the child and others, and treatments that have been tried (Stores & Wiggs, 2001). This indirect assessment approach raises concerns about the reliability and validity of the information gained (Espie & Tweedie, 1991). However, it is considered to be an acceptable form of sleep problem assessment when concentrating on the behavioural effects that sleep problems have on children as well as their parents (Atkinson, Vetere, & Grayson, 1995; Didden & Sigafos, 2001). A sleep diary kept over a two-week period can be

used to give a more detailed account of the sleep problem. This can be more revealing compared to retrospective accounts given by parents, and can examine the child's sleep length, and sleep pattern, as well as what happens during problem times (Durand et al., 1998; Stores & Wiggs, 2001).

Some objective measures can be used to assess sleep problems. Actigraphy is used to determine total sleep duration, number of arousals, as well as sleep latency. Body movements are recorded through a small wrist-watch like computerised device. It is a useful outpatient procedure where the basic sleep-wake pattern (timing, continuity, duration) is the focus of assessment (Corkum, Tannock, & Moldofsky, 1998). Polysomnography allows examination of the stages of sleep as well as sleep architecture. However, this form of sleep assessment is only required in a minority of cases where excessive daytime sleepiness, apnoea, complicated parasomnias, and checks on sleep complaints or treatment response are concerned (Stores & Wiggs, 2001). Furthermore, possible disadvantages of using polysomnography with children include sleeping in an unfamiliar environment that could be threatening to most children, and that the environment itself may not be appropriate for the child (Corkum et al., 1998).

The introduction of home polysomnography can be a useful substitute when objectively assessing sleep problems in children. A small portable recording system is used to investigate sleep without interfering in the child's typical sleep process. Home polysomnography is generally underused, and has not been standardised to match the polysomnography that is performed in the laboratory in an inpatient setting. Hence, for some sleep disorders it is best utilised as a screening device (Stores, 2001a).

Taking a video recording is another useful way of objectively assessing sleep problems in children. This is particularly helpful when the nature and sequence of the sleep problem behaviour is difficult to ascertain. For behavioural sleep problems video recording is also valuable as it allows observation of parental responses to the child's sleep behaviour. The use of an infra-red camera ensures that the child's sleep is not disturbed. To begin with it may be difficult to obtain helpful records, however, over time clinically useful results can be acquired (Stores, 2001a).

Differences in the above types of sleep assessment can make it difficult to compare research findings. However, the majority of sleep studies have used questionnaires, surveys, or sleep diaries to gain information on the nature and prevalence of sleep problems in children.

1.8 Prevalence of Sleep Problems in TD Children

1.8.1 Sleep Problems in Early Childhood

Night waking, night settling, and co-sleeping are the most common sleep disturbances in infants and toddlers. Anders, Halpern, Hua (1992) found that 33% of mothers who were surveyed when their child was 8 months old labelled the child as a problem sleeper. Richman (1981) estimated that between 13% and 20% of 1-2 year olds wake regularly. Furthermore, 62% of children in the waking group displayed bedtime reluctance and long settling times compared to 7% and 13% in the non-waking group respectively.

Scott and Richards (1990) found that 17% of mothers with a TD 1-year-old child reported a moderate or severe sleep problem, and 26% reported that the child woke at night at least five times per week. Armstrong et al. (1994) surveyed 3269 parents of TD children aged up to 38 months. Twenty-three percent of parents with

children aged 1-3 months reported a sleep problem, while 36% of parents with a child aged 7-12 months and 28% of parents with a child aged 25-38 months, stated their child had a sleep problem. In a longitudinal study, Zuckerman, Stevenson, and Bailey (1987) found that 29% of three year olds had a sleep problem; with 18% having difficulty getting to bed/sleep and 22% presenting with night waking problems. Lozoff, Wolf, and Davis (1985) reported that approximately 30% of children between 6 months and 4 years of age exhibited night waking or bedtime struggles that occurred three or more nights per week.

In another study Lozoff, Wolf, and Davis (1984) examined the prevalence and correlates of co-sleeping in children between 6 months and 4 years of age. Thirty-five percent of children in Caucasian families, and 70% in African-American families were classified as co-sleepers where co-sleeping occurred more than once a month. Six percent of children in Caucasian families and 46% in African-American families were classified as frequent all-night co-sleepers. In a replication of this study on a large sample of Hispanic-American children, the reported incidence of frequent, all-night co-sleeping was 21% (Fuchs-Schachter, Fuchs, Bijur, & Stone, 1989). The frequency of co-sleeping is most likely under-reported by parents in the Western world, perhaps due to paediatric prohibition of this practice because of concerns of possible sexual abuse or the prevention of independent development (Thiedke, 2001). However, a clear cultural difference is apparent in regard to frequent all-night co-sleeping, but not in occasional co-sleeping where a significant cultural difference has not been obtained (Fuchs-Schachter et al., 1989).

Co-sleeping tends to persist and is significantly associated with the occurrence of other sleep problems in TD children. Madansky and Edelbrock (1990) assessed the prevalence of co-sleeping in a community sample of parents of 2-3 year

olds, and conducted a 12-month follow up assessment. Approximately 80% of frequent co-sleepers at initial assessment were co-sleeping a year later. Co-sleepers were also two to four times more likely to exhibit bedtime resistance, settling difficulties, and night waking. Other studies have also reported similar findings (Fuchs-Schachter et al., 1989; Lozoff et al., 1984; Lozoff et al., 1985; Zuckerman et al., 1987).

1.8.2 Sleep Problems in Early to Middle Childhood

During early to middle childhood difficulties falling asleep and night waking are also quite common. Owens, Spirito, McGuinn, and Nobile (2000) studied sleep disturbances in children aged 4 to 11 years. Overall, 37% were described as having a significant sleep problem. The most common sleep problem was bedtime resistance with 15.1% of children exhibiting this behaviour. Approximately 10% of children had sleep anxiety problems, while 6.7% displayed night waking difficulties, 12.6% had a parasomnia and 3.7% displayed sleep disordered breathing. Similar prevalence rates were reported by Blader, Koplewicz, Abikoff, and Foley (1997) who surveyed 987 parents of children aged 5 to 12 years. Prevalence rates obtained for bedtime resistance and night waking were 27% and 6.5% respectively. Pollock (1994) found that 25.1% of 5-year-olds had a sleep problem of some kind with 8.8% having difficulty getting to sleep and 10.8% waking during the night. Early waking occurred in 7.2%, nightmares or night terrors in 4.9%, and sleepwalking in approximately 1%. Kahn et al. (1989) reported that 43% of 8 to 10-year-olds had sleeping difficulties that had lasted more than six months. Enuresis occurred in 2%, while somnambulism occurred in 5%, 7% displayed somniloquy, and 15% displayed night fears. These

findings suggest that during early and middle childhood sleep problems are a common occurrence with children experiencing an array of sleep problems.

1.8.3 Sleep Problems During Adolescence

The sleep-wake schedule is more variable in adolescents as parental rules for bedtime decrease and academic and social activities increase. As a result, delayed sleep phase syndrome is a common problem in adolescence. Furthermore, sleep difficulties in this population are more similar to those reported in adults (Dahl, 1995). Data from a large school-based survey examined the prevalence of insomnia as well as hypersomnia and related functioning of adolescents aged 10-17 years. The prevalence rate for adolescents experiencing insomnia was 12.8%, while for hypersomnia it was 6.4%, and for individuals experiencing both problems it was 3.5%. The strongest correlates of sleep problems were disturbed mood, fatigue, and suicidal ideation (Roberts, Roberts, & Chen, 2001).

Wolfson and Carskadon (1998) found that most of the adolescents they surveyed were not getting enough sleep, and that this sleep loss interfered with daytime functioning. In another study of adolescents aged 11-15 years, 12% reported a sleep problem almost every night, while 76% reported experiencing occasional sleep problems. Night waking occurred very often for 7.2% of adolescents, while nightmares were a frequent occurrence for 3.6% of adolescents. Night terrors and sleepwalking occurred frequently for 1.8% and 0.9% of adolescents respectively (Ipsiroglu, Fatemi, Werner, Paditz, & Schwarz, 2002). In another study by Ohayon and Roberts (2001) 8% of adolescents aged 15-18 years had an ICSD dyssomnia or sleep disturbance associated with a mental disorder. Sleep disorders associated with

a mood disorder occurred in 2.1% of adolescents, while 0.5% had a circadian rhythm sleep disorder, 0.4% had obstructive sleep apnoea, and 0.3% had narcolepsy. For the parasomnias, 25.4% exhibited sleep talking, 2.2% had bruxism, 0.3% had nightmares, and none had sleep terrors or sleepwalking.

These findings indicate that sleep problems are relatively common in TD children across all ages, with many parents viewing their child as having a sleep problem. Sleep problems develop early within this population, with many beginning from birth or during early childhood.

1.9 Prevalence of Sleep Problems in Children with an ID

1.9.1 Comparing Children with an ID to TD Children

Some studies have examined and compared sleep problem prevalence rates between TD children and children with an ID. Quine (2001) measured a range of sleep problems in 576 primary school children and 182 children from special schools (aged 4-12 years). Children from special schools had significantly higher prevalence rates for night waking (45%) and night settling (41%) as opposed to TD primary school children (13%, and 27%) respectively. Prevalence rates for co-sleeping (17%) and waking before 5 am (14%) were also significantly higher in children with an ID compared to TD primary school children (11% and 5% respectively). The children from special schools also had significantly higher prevalence rates for features associated with obstructive sleep apnoea, as well as two of the parasomnias: head banging (4%) and bedwetting (33%) compared to the mainstream primary school children (2%, and 5% respectively). Interestingly, on the remaining five parasomnias (sleep talking, sleep walking, bruxism, nightmares, and sleep terrors), no significant

difference was obtained between the two groups with frequencies ranging between 1% and 14%.

Cotton and Richdale (2006) examined and compared parent described sleep problems of children with autism, Down syndrome, Prader-Willi syndrome, an ID of unknown aetiology, and TD children. Across the disorder groups 54.2% of children had a sleep problem, compared to 10.9% of TD children respectively. Similarly, a study by Richdale, Francis, Gavidia-Payne, and Cotton, (2000) showed that children with an ID displayed significantly higher rates of both past (57.7%) and present (66.7%) sleep problems compared to the children in the TD group (16%, and 33.3%) respectively. Thus sleep problems are more prevalent for children who have an ID.

1.9.2 Sleep Problem Variability in Children with an ID

The reported prevalence rates for sleep problems in children with an ID is quite variable. Wiggs, and Stores (1996b) studied the prevalence of sleep problems in 209 children with a severe ID aged 5-16 years. Forty-four percent of the sample had a severe, current sleep problem that occurred most nights or every night. Didden, Korzilius, van Aperlo, van Overloop, and de Vries (2002) used the same questionnaire as Wiggs, and Stores (1996b) to examine the prevalence of sleep problems in 286 children with a mild to profound ID. At least one type of sleep problem was reported for 16.1% of the children, with severe settling problems, night waking and early waking reported for 4.2%, 10.8%, and 4.2% respectively.

Piazza, Fisher, and Kahng (1996) used a 24-hour momentary time sampling procedure for an average of 22 days per patient, to record sleep-wake patterns of 51 children and adults with an ID and severe behaviour disorders. Results showed that 88.2% of the patients presented with a sleep problem on at least 43% of nights. In a

longitudinal study, Quine (1991) used the night waking and night settling items from the Behaviour Screening Questionnaire (Richman, Stevenson, & Graham, 1982) to consider sleep problems of 200 children with a severe ID. Two additional items relating to parental attention, and parents taking their child into bed with them were used to establish the presence of a sleep problem. Overall, 51% of children had a settling problem and 67% had a night waking problem. It was further reported that 62% of children between the ages of 0-5 years had a settling problem, while 84% had a night waking problem. Forty-nine percent of 6-10-year-olds had a settling problem, and 63% displayed night waking problems. For children between 11 to 18 years, 46% had settling problems, and 60% had waking problems.

In an earlier study by Clements, Wing, and Dunn (1986), the sleep disturbance of 155 children with an ID under the age of 15 years was measured via an interview schedule. Thirty-four percent of children were rated as having some type of sleep disturbance. This low prevalence rate is contrasted to that of Bartlett, Rooney, and Spedding (1985), where 214 families completed a questionnaire designed to ascertain nocturnal difficulties faced by the family in the last seven days. Ten sections pertaining to a nocturnal difficulty were included in the questionnaire. Overall, 56.5% had a night waking difficulty, and 56% had a night settling difficulty. Furthermore, 86% of children with an ID who were younger than 6 years, 81% between the ages of 6 to 11 years, and 77% between 11 to 16 years, had one or more nocturnal difficulties.

The variability of prevalence rates across these studies makes it difficult to draw firm conclusions on the frequency of sleep problems in children with an ID, however, it is evident that sleep problems are significantly more prevalent for children with an ID as opposed to TD children. The inconsistent findings across

prevalence studies for children with an ID may be partially attributed to the use of different questionnaires with different definitions of a sleep problem (Clements et al., 1986; Didden & Sigafoos, 2001). Some studies defined a sleep problem purely through reports examining the frequency of disturbances and the duration of settling time. Various criteria were then used to denote those children with a mild or a severe sleep problem (Quine, 1991, 2001; Wiggs & Stores, 1996b). Conversely, when reporting their prevalence rates, other studies have relied on whether or not the parents actually consider their child to have a sleep problem (Bartlett et al., 1985; Clements et al., 1986; Patzold, Richdale, & Tonge, 1998; Richdale et al., 2000). Assessing parental perception for the recognition of a sleep problem can be important due to the differing tolerance levels among parents regarding their child's sleep behaviour (Scott & Richards, 1990). Parental perception of a sleep problem is also important as it determines whether people are likely to seek help for the problem (Wiggs & Stores, 1998b).

The prevalence rate variability reported across studies may also be due to the age of the children, severity of their ID, their living environment, the caregivers' interpretation of the assessment measures used, as well as the combination within studies of children with different types of disabilities (Didden & Sigafoos, 2001). Sleep problem prevalence varies across disorders. Cotton and Richdale (2006) reported higher rates of sleep problems for children with autism compared to children with other disabilities. Thus, it is important to consider the type of disorder when examining sleep problems in children with an ID. The type of disability may play a significant role in the aetiology of the sleep problem, and may also have different implications regarding treatment of the sleep problem (Cotton & Richdale, 2006; Stores, 1992).

While the above issues make it difficult to discern accurate prevalence rates for sleep problems in children with an ID, it is clear that comparatively, such sleep problems are more common in children with an ID as opposed to TD children. A number of factors have been considered in an attempt to explain why the risk of developing sleep problems is higher for children with an ID.

1.10 Aetiology of Sleep Problems in TD Children and Children with an ID

For TD children, the principal cause for the majority of night waking problems is negative or maladaptive sleep onset associations (Mindell, 1997). By the first year of life, the majority of infants have learned to put themselves back to sleep or “self-soothe”, while other infants will cry out or “signal” upon such awakenings (Anders et al., 1992). Children who obtain or require parental assistance as they first fall asleep (such as rocking, feeding, holding) will then need the same conditions in order to return to sleep after normal wakings during the night. Thus, the settling-down ritual involving parental interaction can create a negative sleep-onset association that the child cannot reproduce alone (Trilling, 1989). Over time, the child learns to associate this response with the onset of sleep, and requires further parental attention upon settling to sleep at bedtime and during future normal awakenings (France, Henderson, & Hudson, 1996). Parents who give in to the crying and attend to the child only serve to reinforce the child’s behaviour of crying longer and louder in order to gain parental attention (Durand et al., 1998).

Parents find it increasingly difficult to disengage from this sleep cycle, as not attending to the child results in long bouts of crying, but rapidly responding to the child ameliorates the crying and leads to sleep onset (France et al., 1996). Furthermore, Trilling (1989) states that nighttime separation of the child from the

parent is a recent innovation in human evolution. As such, parents have a biological instinct to attend to their crying child, and this response may also include taking the child into their own bed. Hence, the sleep problem is maintained and the child does not learn to self-soothe because the parents provide attention and reinforcement for disruptive awakenings (Mindell & Durand, 1993). Furthermore, any change in this sequence of events results in aversive consequences for both the child and the parents (France et al., 1996).

For preschool or school age children, stalling or refusal to go to bed is another type of settling problem that typically occurs at bedtime but may also exist after nighttime wakings (ASDA, 2001). Going to bed is avoided by making multiple requests that delay the onset of bedtime, or with the use of emotional outbursts that may last for hours (Durand et al., 1998). This problem is typically maintained by parents who do not set and enforce bedtime limits, and give in to the child's outbursts or demands, hence reinforcing the child's difficult bedtime behaviour (Stores, 1996; Wiggs & Stores, 2001b).

The aetiology of sleep problems in children with an ID are unknown, although an array of physical and psychosocial attributes may make children with an ID highly vulnerable towards these types of sleep problems (Richdale, 1999; Wiggs & Stores, 2001b). As is the case for TD children, it is possible that children with an ID have a negative sleep onset association that is reinforced and maintained by the parents. As is to be expected, having a child with an ID can have a negative impact on parental attitudes, parenting ability, and overall well-being. Parents of children with an ID often face complications such as psychological disturbance, marital disharmony, and guilt. The presence and effect of these factors may make children with an ID susceptible to sleep problems because the parents of these children may

not be able to prevent the negative sleep onset associations from transpiring (Wiggs & Stores, 2001b).

For children who have a severe ID another possible explanation relates to the presence of a potentially different sleep physiology. The presence of a severe ID is usually associated with a highly irregular sleep-wake pattern, and REM sleep deficiency (Espie & Tweedie, 1991; Okawa & Sasaki, 1987). This is due to the damage of various brain structures that regulate sleep and control sleep-wake rhythms (Wiggs & Stores, 2001b). Piazza et al. (1996) observed that children with a severe ID and severe behaviour disorder slept less than TD children at all age levels. Didden, Korzilius, et al. (2002) have also claimed that the frequent use of antiepileptic medications and other drugs common to this population may have a negative effect on sleep-wake patterns.

Physiological abnormalities specific to the child's condition may also be a precursor for sleep problems. For example, Richdale (1999) suggested melatonin production as a possible underlying cause of sleep problems for a subgroup of children with autism. Vela-Bueno, Oliván-Palacios, and Vgontzas (2001) also report on hypothalamic dysfunction, characteristic of Prader-Willi Syndrome, and excessive daytime sleepiness as well as REM sleep abnormalities in this population. The higher rate of sleep problems in children with an ID may also be the result of underlying medical conditions, such as epilepsy, that are associated with sleep problems (Johnson, 1996; Wiggs & Stores, 2001b).

Cognitive, social, and communication deficits are often present in children with an ID, and such impairments may hinder the learning of appropriate behaviour, including sleep behaviour (Johnson, 1996; Wiggs & France, 2000). This is specifically relevant when considering the ability of the child to learn to engage in

self-soothing behaviour during sleep onset or after typical night wakings (Johnson, 1996). Furthermore, sleep problems could arise for children who have a social-communication impairment. These children may find it difficult to apply the social cues that help entrain circadian rhythms and to regulate the sleep-wake cycle (Richdale, 1999). Alternatively, specific skill and communication impairments may thwart the child's capacity to understand and comply with bedtime demands (Johnson, 1996).

Therefore, a range of factors may cause sleep problems in children with an ID. It is also possible that multiple factors may combine to have an additive effect on the sleep of children with an ID. Since the majority of these factors are chronic, sleep problems in children with an ID should be thought of as a potentially long-term problem. In fact, if left untreated they may be very persistent.

1.11 Duration of Sleep Problems

The onset of night waking, night settling, co-sleeping, and early waking sleep problems tends to decrease with age, however, most TD children, as well as children with an ID, do not outgrow these problems as many parents and physicians believe (Durand et al., 1998). Mindell (1997) stated that sleep problems are the most persistent of all child behavioural disturbances. Minde, Faucon, and Falkner (1994) share the view that sleep problems tend to persist over time and cannot be thought of as a short-term occurrence. In their longitudinal study, Zuckerman et al. (1987) examined the continuity of sleep problems in TD children, finding a significant association for sleep problem persistence from 8 months to 3 years of age.

Similar findings have also been obtained in sleep studies conducted on children with an ID. Wiggs and Stores (1996b) reported an average duration of 7

years for sleep problems in children with an ID. Another study found that 58.6 % of children with an ID had a sleep problem that had persisted for two or more years (Richdale et al., 2000). Quine (1991) reported that 48 % of children with an ID who had a settling problem and 66% who had a night waking problem still had the problem three years later. Bramble (1996) also reported that 15 children with a severe ID displayed severe, lifelong settling and waking problems. He further claimed that such problems sometimes continue into adulthood. This is evidenced in the study of Brylewski and Wiggs (1998) who examined the sleep of 210 adults with an ID for the existence of sleep problems. Information about sleep disorders and behaviours during the previous month revealed that 26.8 % of adults with an ID showed settling problems as indicated by carers, while 55.6 % demonstrated night waking behaviour that required carer attention and was reported to be problematic.

Thus, sleep problems that are behavioural in nature appear to be difficult to resolve with many parents reporting the problem continues for a number of years. This is especially the case for parents who have a child with an ID, and indicates that professional intervention is required for many of these families in order to improve the sleep problem.

1.12 Concluding Comments

Throughout childhood and adolescence sleep problems are a common occurrence with co-sleeping, night settling, night waking, and early waking reported most often. These types of sleep problems are also persistent, often lasting for many years. However, clear prevalence rates for sleep problems in children with an ID have not been obtained with a high degree of variability reported across research studies. Different definitions and criteria for what constitutes a sleep problem,

different sleep assessment measures, and a lack of homogeneity regarding type of ID within and across studies are possible explanations for differing prevalence rates. Despite such shortcomings, it is clear that children with an ID experience sleep problems at a significantly higher rate than TD children. The high prevalence rates, chronic nature, and ambiguous aetiology of sleep problems in children with an ID warrant further investigation. The next chapter is a review of studies that have reported findings outlining various child and parent factors that are associated with the presence of sleep problems in children with an ID.

CHAPTER 2. FACTORS ASSOCIATED WITH SLEEP PROBLEMS

In order to effectively treat sleep problems in children a complete understanding of the nature of such problems is imperative. This chapter reviews the studies that have explored factors linked to sleep problems in TD children and children with an ID. For night waking, night settling, co-sleeping, and early waking sleep problems, parents are often implicated in the establishment or maintenance of the problem. Therefore, it is important to examine the association between sleep problems and various child and parent factors as this would have implications regarding the treatment of such problems.

2.1 Sleep Problems and Related Child Factors

Child characteristics that have been examined for an association with sleep problems in TD children or children with an ID have included infant temperament, the child's age, medical conditions and medication use, adaptive behaviour, daytime behaviour, and level of severity of ID.

2.1.1 Infant Temperament

It has been reported that children with certain individual characteristics or temperaments may not readily adopt self soothing sleep techniques, and may be more likely to engage in difficult behaviours such as night waking (Richman, 1981; Atkinson et al., 1995). In Richman's (1981) study children aged 1-2 years with a waking problem were significantly less malleable, and also less rhythmic in their habits than the children in the control group. Atkinson et al. (1995) examined the

temperament profiles of toddlers with a sleep problem compared to those without sleep problems. The 57 toddlers were matched on age, and came from similar environments and accommodation. A significant positive correlation between difficult temperament and the existence of sleep problems was obtained. More specifically, when maternal perceptions were used to define toddlers in the sleep problem group these children were found to be significantly less adaptable, more likely to withdraw when confronted with new stimuli, and less rhythmic in their behaviour. These results are similar to previous findings (Jimmerson, 1991; Schaefer, 1990).

Scher, Epstein, Sadeh, Tirosh, and Lavie (1992) monitored the sleep of 31 TD toddlers using both maternal report and actigraphy. Analysis for nine temperament categories revealed a modest association between sleep and temperament, with toddlers who were perceived as non-adaptable and distractible generally having less sleep. Increased rhythmicity was associated with shorter sleep duration and few awakenings, while children who were who were perceived to be high on the approach dimension fell asleep later, woke up later, and had more sleep disruptions compared to more approachable children. Children who were less adaptable and more distractible also slept less, while persistence was associated with greater sleep efficiency.

Novosad, Freudigman, and Thoman (1999) studied the sleep patterns of 41 TD, new-born infants during the first two postnatal days, and compared this to their temperament as measured at 8 months. For the first day of sleep, infants classified in the most difficult temperament group displayed a sleep profile that differed significantly from infants in the other temperament groups. The most difficult infants

were less rhythmic, less approaching, more intense, and more negative in mood and showed high variability with extreme values on all sleep measures.

This research demonstrates that infant characteristics are related to sleep problem incidence in TD children. Infants lower on rhythmicity, and adaptability, and who are less approaching are more likely to have sleep problems, especially night waking, during their first 2 years.

2.1.2 Sleep Problem Occurrence and Age

Another factor to be considered is whether or not the prevalence of children's sleep problems vary with age. In a study of 987 TD children aged 5 to 12 years, Blader et al. (1997) reported significantly higher rates of night waking in younger children. Owens et al. (2000) examined the sleep habits of 494 TD children aged 4 to 11 years. Younger children had more bedtime struggles and night wakings than the older children.

Quine (2001) assessed prevalence rates for dyssomnias, parasomnias, and features associated with obstructive sleep apnoea for 576 TD children and 182 children with an ID aged 4 to 12 years. For the children attending mainstream school, rates of settling problems, night waking problems, co-sleeping, early waking, and daytime sleepiness were significantly higher for younger children. There were no age differences on rates of parasomnias for this population. For the children attending special school, only rates of night waking and co-sleeping were significantly higher for younger children. Prevalence rates of parasomnias and features associated with obstructive sleep apnoea were not related to age in the children attending special school.

Clements et al. (1986) reported a strong link between age and sleep problems, with more than 50% of children with an ID under the age of 5 years displaying night waking or limited hours of sleep. Wiggs and Stores (1996a) also found a significant association between age and the presence of sleep problems in children with an ID, with younger children more likely to have one or a combination of settling, night waking, and early waking sleep problems. In a longitudinal study of 200 children with a severe ID, Quine (1991) reported that a lack of sleep, and night waking were associated with the age of the child, while night settling problems were not.

Conversely, Bartlett et al. (1985) recorded equally high prevalence rates of sleep problems for children with an ID who were aged less than 6 years, 6-10 years, and 11-16 years respectively. Similarly, Schreck and Mulick (2000) examined sleep problems in children with a general ID, as well as in children with a pervasive developmental disorder: Age did not contribute to sleep quantity or quality in either group. Likewise, Robinson and Richdale (2004) did not find a significant association between age and the presence of past or current sleep problems in their first study, and Didden, Korzilius, et al. (2002) did not find a significant correlation between sleep problem prevalence and age groups.

For TD children, a clear link has been established between age and the presence of sleep problems. Younger children are more likely to present with night waking, co-sleeping, night settling, and early morning waking problems as opposed to older children. However, for children with an ID the results are less definitive. There is evidence to suggest that night waking and co-sleeping are more prevalent in younger children with an ID, while night settling and early morning waking sleep problems appear to present equally across age.

2.1.3 Medical Conditions and Medication Use

There are numerous medical and surgical conditions that are associated with significant sleep disturbance in children. Furthermore, the use of prescription and non-prescription medications can greatly alter the sleep of children (Mindell & Owens, 2003). Blader et al. (1997) found that sleep onset problems were a significant predictor of medical illness, while bedtime resistance was not. Pollock (1994) reported that night waking at 5 years of age was associated with chronic medical conditions at 10 years of age. Night wakers were significantly more likely to have presented with eczema, recurrent abdominal pain, wheezing, a history of whooping cough, and visits to a general practitioner in the past 12 months.

Using multiple regression, Quine (2001) found that child's health status was one of three variables significantly associated with settling problems in children attending mainstream school. Also, the child's health status and the presence of problems requiring night attention were two out of five variables significantly associated with night waking problems in children attending mainstream school. For children attending special school the presence of problems requiring night attention was one of three variables significantly associated with night waking problems.

Didden, Korzilius, et al. (2002) also found that children with an ID who had severe sleep problems used medication more often than those without sleep problems. However, Clements et al. (1986) did not find an association between sleep problems in children with an ID and psychotropic or anticonvulsant medication usage. Bartlett et al. (1985) reported that the prevalence of sleep difficulties did not differ significantly for children with an ID who were taking anticonvulsants. In their first study, Robinson and Richdale (2004) also failed to find a relationship between past or present sleep problems in children with an ID and medication usage in the

previous six months. The presence of a medical condition also was not associated with sleep problem occurrence.

Two specific medical conditions that have been considered in relation to the presence of sleep problems in children are epilepsy and asthma. Epilepsy is a chronic neurological disorder, and sleep or arousal from sleep can often trigger epileptic seizures for many people who suffer from this condition (Shouse & Mahowald, 2005). Furthermore, seizures are more common in people who have an ID, further complicating the issue of sleep problems in these children (Stores, 1992). Both Didden, Korzilius, et al. (2002) and Quine (1991) reported significantly higher prevalence rates for sleep problems in children with an ID who had epilepsy as opposed to those children without epilepsy. This finding has also been reported in TD children (Becker, Fennell, & Carney, 2003; Stores, Wiggs, & Campling, 1998). It is difficult to draw firm conclusions regarding epilepsy and the association with sleep problem occurrence as there are many different types of epilepsy that vary in aetiology, nature, severity, age of onset, prognosis, and treatment (Stores, 1992).

Asthma is the most chronic of all childhood illnesses and prevalence rates in Australia are high compared to other countries. In Australia asthma affects 14-16% of children, and 10-12% of adults, with approximately 10% of children experiencing asthma related sleep disturbance (Marks, Correll, & Williamson, 2005; Robertson, Roberts, & Kappers, 2004).

Sadeh, Horowitz, Wolach-Benodis, and Wolach (1998) assessed the sleep and pulmonary function in children with and without asthma aged from 8 to 15 years. In a home-based, objective study the children were monitored for three days with wrist actigraphs and peak-flow meters to estimate asthma severity. The children with asthma had significantly lower peak flow means on morning measurement as

well as a significantly larger drop in peak flow measures from the evening to the morning. The children with asthma were significantly more active during sleep, and had a lower percentage of sleep without motion. On self-rating scales children with asthma rated themselves as significantly more tired in the morning, having greater difficulty in waking up in the morning, and having a preference for late bedtime. Parents also rated the children with asthma as being significantly more tired in the morning, less alert, and more restless during sleep than the control children.

These findings are similar to those obtained in another study where home polysomnography and parental ratings of sleep quality and daytime sleepiness were compared in children with nocturnal asthma and children without asthma (Stores, Ellis, Wiggs, Crawford, & Thomson, 1998). The sleep efficiency of the children with asthma was significantly lower as a result of higher rates of disruption by awakenings as compared to the children without asthma. Furthermore, parental ratings of impaired sleep quality and daytime sleepiness were significantly higher for the children with asthma as compared to those without asthma. A treatment phase for this study was also conducted and a change of anti-asthma treatment for nocturnal symptoms was associated with a significant decrease in the number of awakenings. However, maternal reports did not yield significant improvements in the sleep quality or daytime sleepiness of the child.

These results contrast those of Tirosh, et al. (1993) who used a parent report survey to investigate the association between asthma and sleep in children aged 4 to 48 months. The number of waking nights per week as well as wakings per night, settling time, wake time, and sleep duration of the children with asthma were not significantly different to those of children without asthma. The discrepancy between this finding and those reviewed above may be explained by the fact that this study

was conducted on a younger age group, and used a subjective method of sleep problem assessment. While Stores et al. (1998) found an association between sleep quality and daytime sleepiness using parental reports, they also claimed that subjective reporting failed to reliably distinguish those children with asthma who had slept badly from those who slept well. Hence, using purely subjective methods may underestimate the association between sleep problems and asthma.

For TD children there appears to be a clear association between sleep problems and medical conditions or poorer health of the child. Specifically, asthma and epilepsy are associated with a greater prevalence of sleep problems in TD children. However, the results are less conclusive for children with an ID with some studies finding clear associations between sleep problems and the presence of medical conditions and medication use, while other studies have not. Contrasting results have also been obtained regarding sleep problem prevalence, epilepsy, and the use of anti-convulsant medication.

Perhaps the most telling finding is that reported by Quine (2001) where poorer child health status was associated with settling and waking difficulties for mainstream children but not children attending special school. It may be that parents of a TD child with a medical condition or poor health are more indulgent towards the child and less stringent regarding bedtime behaviour than if the child is generally healthy (Quine, 2001). However, parents who have a child with an ID may make similar bedtime allowances as a result of their child having a disability regardless of whether the child has a medical condition or poor health.

2.1.4 Adaptive and Daytime Behaviour

In a study of 972 TD school children aged 8 to 10 years, Kahn et al. (1989) found that school achievement difficulties were encountered significantly more often among children with poor sleep compared to children without sleep problems. Twenty-one percent of children who exhibited poor sleep had failed one or more years at school, compared to 11% of children in the no sleep problem group. Bates, Viken, Alexander, Beyers, and Stockton (2002) considered the sleep patterns of 202 TD children aged 4-5 years living in a predominantly low-income community setting. Daily logs of the child's sleep revealed that disrupted sleep patterns predicted less optimal adjustment in pre-school, even when the roles of family stress and family management practices had been considered.

However, Pollock (1994) did not obtain a distinct difference between the educational achievements of TD children with night waking problems compared to those without waking problems. Maternal reports of difficulties with writing, maths, and verbal or non-verbal skills also did not differ significantly between children with waking problems and those without waking problems. There was also no difference between the two groups of children in relation to speech difficulties, but those with waking difficulties were significantly more likely to have an eating or appetite problem. In other studies of TD children sleep problems have been significantly associated with social problems within the child (Aronen, Paavonen, Fjällberg, Soininen, & Törrönen, 2000; Paavonen, Solantaus, Almqvist, & Aronen, 2003).

Conversely, in their longitudinal study of 308 TD children Zuckerman et al. (1987) did not find a significant association between eating problems, soiling problems, difficulty playing with siblings or peers, and persistent sleep problems. In their study persistent sleep problems at 3 years of age were significantly associated

with more behaviour problems. Specifically, the children with persistent sleep problems were more likely to display tantrums, and were more difficult to manage in general. Hence, they suggested that persistent sleep problems are one part of a pattern of multiple behavioural problems reflecting pervasive parent-child difficulties. This finding is supported by Lam, Hiscock, and Wake, (2003) who conducted a longitudinal study of 114 TD children aged 3-4 years who had displayed sleep problems in infancy. Children with sleep problems had significantly higher scores on the internalising behaviour, externalising behaviour, aggressive behaviour, and somatic problems subscales of the Child Behaviour Checklist (Achenbach, 1991).

The important link between sleep problems and behavioural problems was further explored by Gregory and O'Connor (2002) who performed a longitudinal study from preschool through to adolescence. Data were obtained for 360 adoptive and non-adoptive, TD children at 4 years of age, and then again at age 15. Using the Child Behaviour Checklist, sleep problems at age 4 were associated with behavioural and emotional problems at age 15 after accounting for child sex, adoptive status, and stability of behavioural/emotional problems. While the sleep problems were a robust predictor of behavioural/emotional problems there was less evidence of a reverse effect, implying that early sleep problems may forecast later behavioural/emotional difficulties.

Cross-sectional studies have also shown an association between the presence of sleep problems and behavioural problems. Lavigne et al. (1999) examined the relationship between sleep and behaviour problems in 510 TD children. They found a significant relationship between lower amounts of sleep and externalising behaviours such as hyperactivity, aggression, and non-compliance. Owens-Stively et

al. (1997) also found that age and behavioural problems best predicted the occurrence of sleep disturbances in TD children.

Similar sleep-behaviour associations have been obtained for children with an ID. Using the Aberrant Behaviour Checklist (Aman & Singh, 1986) a number of studies have reported a significant association between severe sleep problems in children with an ID and daytime behaviour (Didden, Korzilius, et al., 2002; Wiggs & Stores, 1996a; Wiggs & Stores, 1998b). In addition, Richdale et al. (2000) reported that the presence of sleep problems was significantly associated with the total behaviour score, disruptive, and self-absorbed subscales of the Developmental Behaviour Checklist (Einfeld & Tonge, 1994). Patzold et al. (1998) also obtained a significant association between the existence of past and current sleep problems and the total problem behaviour score of the Developmental Behaviour Checklist. Similarly, they found that severity of past sleep problems and the presence of a current sleep problem were associated with the total problem behaviour score of the Child Behaviour Checklist.

Quine (1991) found that children with an ID and sleep problems demonstrated significantly poorer use and understanding of communication compared to children in the no sleep problem group. Thirty-five percent of children with sleep problems were classified as having poor receptive communication, while 40% had poor expressive communication. In contrast, in the no sleep problem group 9% and 13% were reported as having poor receptive and expressive communication respectively. Other significant associations between the occurrence of sleep problems in children with an ID included poorer self-help skills, poorer reading, writing, and counting skills, as well as higher levels of incontinence. Wiggs and Stores (1998b) reported significantly higher scores on the inappropriate speech factor

of the Child Behaviour Checklist for children with an ID who had a sleep problem as compared to those who did not have a sleep problem. Piazza et al. (1996) reported that total appropriate sleep time had a significant positive correlation with expressive language but not with receptive language. In their study of adults with an ID Brylewski and Wiggs (1998) also reported that communication difficulty was significantly associated with sleep problems. Fifty-nine percent of adults with poorer communication reported night waking compared to 44% of adults who were more communicative.

However, other research studies have provided contradictory findings to those reported above. For example, other studies have not found an association between sleep problems and the inappropriate speech factor of the Child Behaviour Checklist (Wiggs & Stores, 1996a; Didden, Korzilius, et al., 2002). Clements et al. (1986) also found sleep problems were not significantly associated with use and comprehension of speech, communication with adults or peers, incontinence, or various self-help skills. Instead, they reported that self-injury, attachment to routines, and non-socially directed difficult behaviour were the child behaviour characteristics that were significantly associated with sleep problems in children with an ID.

Findings across studies have not revealed consistent associations between communication, academic, self-help, other adaptive behaviours, and sleep problems in TD children or children with an ID. There is a paucity of studies dedicated to sleep problems and adaptive behaviour in children, and the use of different measures to classify sleep problems and assess adaptive behaviour further confounds this issue. A combined study of both TD children and children with an ID might be useful to determine if any specific adaptive behaviours are associated with sleep problems in one population but not the other.

In contrast, for both TD children and children with an ID a strong association has been found between sleep problems and the occurrence of daytime behaviour problems. Furthermore, longitudinal studies have revealed that persistent sleep problems in TD children have predicted future daytime behaviour problems, and one longitudinal study indicated that early sleep problems may forecast behavioural and emotional problems at adolescence. From these results it is not possible to ascertain a causal pathway between sleep problems and behavioural problems. The relationship between sleep and behaviour problems may be the result of the child's sleep problem causing a disturbance to the child's daytime functioning that in turn leads to behavioural problems. Alternatively, children with behavioural problems could be more difficult to manage at bedtime and this could be the cause of the child's sleep problem. Or perhaps some other variables have an underlying factor and influence this relationship. For children with an ID the severity of the child's ID has also been considered in relation to sleep problem occurrence.

2.1.5 The Role of Severity of Intellectual Disability for Sleep Problems in Children with an ID

There has been some consideration of the child's level of severity in relation to the presence of sleep problems in children with an ID. Didden, Korzilius, et al. (2002) examined the prevalence of sleep problems in 286 children with a mild to profound level of ID. They reported a significantly higher prevalence of sleep problems as the level of severity of child ID increased. Those children with more severe levels of ID also took longer to fall asleep at bedtime, as well as during the night after awakenings. Piazza et al. (1996) found that total appropriate sleep was positively correlated with IQ scores, indicating that both the amount and timing of

sleep is related to cognitive functioning. In their first study, Robinson and Richdale (2004) also reported a significant association between severe/profound level of ID and prevalence of both past and present sleep problems. However, findings by Patzold et al. (1998) suggested that sleep problems for children with a pervasive developmental disorder are not related to intelligence level. Based on psychological assessment reports, children were divided into a low intelligence group and a high intelligence group. No significant associations were obtained. Clements et al. (1986) also did not find an association between sleep problems in children with an ID and level of intellectual disability. Similarly, Richdale, et al. (2000) found the frequency of past and present sleep problems did not differ with the level of ID. However, there was a trend for sleep problems to occur more frequently in children with a more severe ID in this study.

The research to date concerning sleep problems in children with an ID and level of severity of ID has provided contradictory findings. It could be difficult to establish this association because of the influence of other factors related to severity of ID, such as the child's specific disability, the presence of various medical conditions, and medication use.

2.2 Parent Factors Associated with Children's Sleep Problems

Parent characteristics that have been examined for an association with sleep problems in TD children and/or children with an ID have included perinatal factors associated with the mother, maternal attachment, personality, maternal stress and depression, locus of control, and perceived control. This section provides a review of the literature regarding each of these factors in relation to sleep problems in children.

2.2.1 Perinatal Factors

Problems occurring during pregnancy, labour, and delivery have been associated with the presence of night waking problems in children. Blurton Jones, Rossetti Ferreira, Farquar Brown, and Macdonald (1978) performed a longitudinal study examining the sleep of 59 TD children at age 15 months, continuing at six-monthly intervals up until age 39 months. Night waking at 15 months was related to sub-optimal obstetric measures. Obstetric factors and reported child behaviour in early infancy were the best indicators of later night waking. It was also reported that the mothers of wakers attended to their child sooner and more often when the child cried compared to mothers of non-wakers.

Armstrong, O'Donnell, McCallum, and Dadds (1998) compared mothers presenting to hospital for their infant's sleep problem with a control group of mothers on variables such as work, medical condition, medication use, beverage, alcohol, cigarette, and marijuana intake during pregnancy. Maternal sleep during pregnancy and emotional adjustment during pregnancy, and postnatal distress were also considered. Poorer maternal sleep during pregnancy was the only variable associated with infant sleep disturbance. Mothers with an infant sleep problem reported significantly greater sleep difficulties themselves in all stages of the pregnancy compared to control mothers. This finding contrasts that of Scher, Richardson, Coble, Day, and Stoffer (1988) who found that pre-natal exposure to alcohol and marijuana intake was linked to infant sleep disorders (Scher, Richardson, Coble, Day, & Stoffer, 1988).

Richman (1981) compared the characteristics of 55 TD 1-to-2-year-olds who had severe waking problems with those of 30 non-waking control children. Analysis revealed that a significantly higher number of children with waking problems had

been placed at clinical risk as a result of one or more severe, adverse perinatal events. However, no differences were reported between the two groups on the mean scores of obstetrical adverse events, or the mean Apgar score as recorded in each child's birth records. Similarly, Chavin and Tinson (1980) did not find a correlation between birth history and sleep problem development.

The results from these limited number of studies prohibit firm conclusions being drawn regarding the relationship between perinatal factors, maternal sleep disturbance during pregnancy and the existence of childhood sleep problems.

2.2.2 Maternal Attachment

The early mother-child relationship is thought to play an important role in an individual's later functioning and the relationship between maternal attachment and sleep problems has also been examined. Sleep is considered important to the attachment process as bedtime is associated with separation and can lead to heightened anxiety and uncertainty in the mother, the child or both. Benoit, Zeanah, Boucher, and Minde (1992) investigated the association of sleep problems with attachment, self-esteem, social support, and marital relationship of 41 mothers of TD toddlers. An adult attachment interview was used to measure each mother's internal working model of attachment, and consisted of enquiries about recollection of early relationships with attachment figures. The sole significant finding of this study was that mothers of toddlers with sleep problems had less autonomous (secure) attachment to the child than mothers' with toddlers with no sleep difficulties. All of the mothers of sleep problem children were classified as insecure with respect to attachment, as opposed to 57% of mothers in the control group. Lozoff et al. (1985)

also reported that maternal ambivalence towards the child was one of five factors separating TD children with sleep problems from children without sleep problems.

Therefore, insecure attachment may be an important factor in the development of sleep problems. However, these results are based on relatively small sample sizes. Furthermore, maternal attachment has not been considered in longitudinal studies or on studies of school age children. In addition, the role of maternal attachment to the child has not been examined in relation to sleep problems for families who have a child with an ID. Considering the higher rates of stress and psychological disturbance in parents who have a child with an ID, such a study should be considered.

2.2.3 Maternal stress and depression

For TD children, a clear link between sleep problem occurrence and maternal stress and depression has been established. Armstrong et al. (1998) compared the ratings of maternal distress of 47 mothers who had presented for admission to a mother/baby hospital due to their infant's sleep problem, with 50 control mothers who had infants of a similar age. The mothers of children with sleep problems obtained significantly higher scores compared to the control group on the postnatal depression scale. This finding supports that of Lozoff et al. (1985) where higher ratings of maternal depressed mood were one of five factors that distinguished TD children with sleep problems from those without sleep problems. An accident or illness in the family, and unaccustomed absence of mother during the day were two specific stressful life events that also distinguished the children with sleep problems from those without sleep problems. Furthermore, in a longitudinal study, Zuckerman et al. (1987) revealed that scores on maternal depression when the infant was eight

months of age were significantly associated with persistent sleep problems that were still present when the child was three years of age.

More recently, Lam et al. (2003) reported that scores on maternal depression were significantly higher in mothers of TD children who had a sleep problem as compared to those who had a child without a sleep problem. This finding has also been reported in similar studies (Hiscock & Wake, 2001; Richman, 1981; Scott & Richards, 1990). However, Lam et al. (2003) did not find an association between sleep problems in TD children and maternal stress. This does not support the finding of Quine (2001) where maternal stress was associated with settling problems, night waking problems, and with co-sleeping problems of children attending mainstream schools.

For the children attending special school in Quine's (2001) study, maternal stress was associated with settling problems, and night waking problems, but not with co-sleeping in the parents' bed. Richdale et al. (2000) considered the association between sleep problems in children with an ID and parental stress. This allowed for the differentiation between the frequency in which stressors occur, and the intensity with which they are felt. Sleep problems were found to be significantly associated with parental ratings of both frequency and intensity of hassles.

The association of sleep problems with stress is further supported by Wiggs and Stores (1998b) where maternal stress was compared between three groups of children with an ID. The first group of children with an ID had a sleep problem, while the second group did not have a sleep problem. The third group of children in the study had a sleep problem that was not recognised by the child's parents. Mothers of children with an ID and sleep problems displayed significantly higher stress levels than mothers of children with an ID and unrecognised sleep problems

and mothers of children with an ID and no sleep problem. The mothers in the unrecognised sleep problem group considered their child's sleep to be unsatisfactory, however, they did not report the critical stress levels of mothers whose child had a recognised sleep problem. Thus, it was thought that mothers of children with an unrecognised sleep problem might have protective factors that serve to increase their resilience. The two factors that were considered as safeguards against stress in this study were locus of control, and perceived control.

The evidence from the above research studies is clearly indicative of a strong link between stress and depression and the presence of sleep problems for TD children, and a strong link between stress and sleep problems for children with an ID. More importantly, one study in relation to sleep problems in children with an ID has found that low levels of maternal stress are associated with a lack of perception that the child has a sleep problem, even though the criteria for the presence of a severe sleep problem were met. This suggests that stress-mediating factors such as maternal locus of control and maternal perceived control may be important factors associated with reporting the presence of sleep problems in children with an ID.

2.2.4 Personality

While personality theorists have not agreed on a global definition, personality may be conceived as:

A pattern of relatively permanent traits, dispositions, or characteristics that give some measure of consistency to a person's behaviour. More specifically, personality consists of traits or dispositions that lead to individual differences in behaviour, consistency of behaviour over time, and consistency of behaviour across situations. (Feist & Feist, 2002, *p.4*)

Understandably, formulating the various determinants that may account for individual differences in human behaviour is an onerous task, and has led to the postulation of numerous personality theories. These theories can be categorised into four main approaches: Psychodynamic, dispositional or biological, humanistic or existential, and learning approaches. Due to the diversity across theories, as well as disagreements over concepts, methodology, and application, no one theory of personality has prevailed above all others (Aiken, 1993).

In order to gain a further understanding of common childhood sleep problems it is important to consider whether or not there is a link between the presence of sleep problems and parent personality. As personality indicates a predisposition to behave in a certain way, this could have implications regarding the development and maintenance of childhood night settling, night waking and co-sleeping problems. Whether or not parents would seek professional help for such problems, and treatment effectiveness could also be affected. To date two personality theories have been considered in association with common sleep problems of childhood, and will therefore be considered here: Eysenck's factor theory, and Rotter's social learning theory. Each theory will be presented, and any association between each personality theory and the presence of sleep problems in children will be explored.

2.2.4.1 Eysenck's factor theory.

Eysenck (1967) postulated the existence of two independent personality dimensions, extraversion-introversion and neuroticism-stability that are largely genetically determined. Due to the different biological thresholds for specific emotional and motivational states, it is thought that personality predisposes individuals to a certain affective style. Extraverts are likely to experience positive

affect more often than introverts, while neurotic individuals are likely to experience negative affect more frequently than stable individuals (Eysenck & Eysenck, 1985).

These two personality dimensions have also been associated with stress responses. Using an in vivo mood induction procedure on 67 college undergraduates, Larsen and Ketelaar (1989) revealed that people who differ on personality dimensions demonstrate different emotional responses given the same stimulus conditions. Specifically, extroverts displayed heightened emotional reactivity to positive mood induction procedures, while neurotics showed heightened emotional reactivity to negative mood induction procedures. Gallagher (1990) argued that a person's appraisals of stressful situations were dependent on the individual's personality. Underlying extraversion leads to reward sensitivity, and thus extraverts viewed stressful events as challenges because they were seen as an opportunity for reward. Conversely, underlying neuroticism leads to punishment sensitivity, and hence neurotics viewed stressful events as threatening because they were seen as an opportunity for punishment.

Considering this association between personality dimensions and stress response, Gelman, Jory, and Macris (1998) examined the role of maternal personality in relation to sleep problems in TD children. Thirty-two mothers with a child between the ages of 10 months and 5 years were recruited from a sleep clinic. They were compared to a control group of 32 mothers living in similar locations, with the control group children matched according to age, sex, and birth order. The mothers with a child who had a sleep problem were significantly more introverted or neurotic than control mothers. As a result of the findings, the authors stated that mothers high on introversion or neuroticism could experience a negative mood state in response to their child's sleep problem and could have great difficulty

implementing behavioural interventions for their child's sleep problem. Consequently, they suggested that counselling would be a better form of sleep problem treatment for these families, and that the counselling should aim to help mothers recognise their concerns, and personality style, and thus reduce their anxiety. However, to date, research has not examined whether sleep problems in children with an ID are associated with parent extraversion or neuroticism.

2.2.4.2 Rotter's social learning theory.

Social learning theory proposes that perceived reinforcement of an event fluctuates between individuals, and this fluctuation depends largely upon whether the individual perceives an association between the reward and their own behaviour (Rotter, 1966). Individuals displaying a general expectation that reinforcement is contingent upon one's own behaviour, or relatively permanent characteristics, are classified as having an internal locus of control belief. Conversely, people with a general expectation that reinforcement is typically a function of luck, chance, fate, or is under the control of powerful others, are classified as having an external locus of control (Rotter, 1966). Locus of control has become one of the most studied variables in psychology, and researchers have examined its role as a stress-moderator (Lefcourt & Davidson-Katz, 1991; Rotter, 1990).

Locus of control is thought to moderate stress by having a direct effect on the individual's coping processes. That is, people with an internal locus of control believe outcomes are within their control, and are therefore active copers. The literature on this topic offers tentative support for locus of control acting as a stress-moderator (Cohen & Edwards, 1989). In a study by Johnson and Sarason (1978) negative life change was associated with depression and trait anxiety for participants

who displayed an external locus of control. In another study (Lawler & Schmied, 1992), external locus of control was associated with greater illness frequency and severity. Furthermore, results supported the notion that locus of control acts as a stress buffer. Participants with an internal locus of control displayed increases in stress that were not accompanied by increases in illness, while those with an external locus of control showed increased stress accompanied by increases in illness.

Furthermore, Kobasa (1979) reported that executives with high stress, and low illness were distinguished on a number of variables, including the presence of an internal locus of control. Lakey (1988) also found that participants with an internal locus of control did not show a change in depression scores when they experienced stressful events, as compared to those with an external locus of control who displayed striking increases in depression following stressful events.

However, other studies have failed to obtain direct support for locus of control as a singular moderator of stress, reporting that locus of control only had such an effect when interacting with other variables such as gender and social support (Sandler & Lakey, 1982; Lefcourt, Martin, & Saleh, 1984; Nelson & Cohen, 1983; Caldwell, Pearson, & Chin, 1987). Thus, it appears that although locus of control can act as a stress-moderator, this process may be complex.

An association between locus of control and parental stress has been investigated for parents of TD children and parents of children with an ID. Mouton and Tuma (1988) compared stress levels, locus of control, and role-satisfaction in clinic and control mothers of TD children aged 2 to 10 years. Clinic mothers had a child with behavioural difficulties while control mothers had never sought psychological services for their child. A strong correlation was obtained between stress and locus of control as it related to the role of parenting. Clinic mothers

displayed higher levels of stress and higher levels of external locus of control, indicating that their child's behaviour was outside of their control.

McKinney and Peterson (1987) examined stress moderation in mothers of children with an ID who were aged from 7 months to 41 months. Mothers with an internal locus of control reported lower stress scores than those with an external locus of control. Furthermore, Friedrich, Wiltner, and Cohen (1985) examined maternal locus of control for mothers of school age children who had an ID. They found that mothers with an internal locus of control experienced fewer personal and family problems. Rimmerman (1991) conducted a study on 24 Jewish mothers who had a child with a severe ID. The study considered variables that appear to moderate the effects of stress. Measures of locus of control, perceptions of the availability of social support, and maternal pessimism towards their child with an ID were obtained. Locus of control and perception of social support both served as buffers against parental pessimism towards children with an ID. Hence, mothers with an internal locus of control may make better use of social resources and possess more optimism about their child with an ID.

To date, one study has considered maternal locus of control and stress in mothers who have a child with an ID and a sleep problem. Based on past literature from other contexts that have considered locus of control acting as a stress moderator, Wiggs and Stores (1998b) hypothesised that mothers of children with an ID and a sleep problem that was not recognised would report less stress and a more powerful internal locus of control than mothers who recognised that their child had a sleep problem. The mothers in the unrecognised sleep problem group did report significantly lower levels of stress, but a higher internal locus of control was not found. Although a trend regarding locus of control was obtained, with the mothers in

the sleep problem group displaying a locus of control pattern that was associated with a more negative reaction to stressful events. The authors proposed that the restricted range of scores obtained by mothers in the sleep problem group prevented any substantial conclusions from being drawn, and called for further exploration of this issue.

2.2.5 Perceived control

Perceived control is another factor that has been implicated as a stress-moderator. Perceived control is different from locus of control in that it relates to a situation-specific expectation, whereas locus of control is a stable disposition or generalised belief (Lazarus & Folkman, 1984). Essentially, the distinction between locus of control and perceived control resembles that of state and trait anxiety. Therefore, an individual who possesses an internal locus of control can still report a low level of perceived control over a particular situation or event, and vice versa.

Lazarus (1966) asserted that a person's belief about their control in a threatening situation would have an effect on stress levels. Specifically, less perceived control over the situation is indicative of higher stress. This notion was supported in a study where higher anxiety was reported for a group of participants who were led to believe that shock was unavoidable (Houston, 1972). Langer, Janis, and Wolfer (1975) reported that inducing perceived control over stress in hospital patients resulted in less anxiety and fewer requests for pain relief medications. Perceived control has also been examined as a predictor of adjustment and recovery from a cardiac event (Moser & Dracup, 1995). Those patients with higher perceived control had lower levels of anxiety, depression, hostility, and also displayed greater psychosocial adjustment six months after their cardiac event. In another study, high

levels of perceived control were related to lower levels of anxiety, hostility, and depression, as well as better adjustment in parents who had an infant hospitalised in a neonatal intensive care unit (Doering, Moser, & Dracup, 2000).

Wiggs and Stores (1998b) reported that perceived control may be an important stress-moderator for parents who have children with an ID and sleep problems. Using visual analogue scales, parents rated their perceived control over any difficult sleep behaviour and any difficult daytime behaviour. Mothers in the sleep problem group perceived themselves as less able to control their child's sleep behaviour than mothers in the unrecognised sleep problem group. Furthermore, there was no difference regarding perceived control between the no sleep problem group and the unrecognised sleep problem group. The authors concluded that perceived control as a form of intervention, or as a component of intervention, should be further investigated.

2.3 Quine's longitudinal Sleep Study

The most comprehensive research to date has been that of Quine (1991) who conducted a three-year longitudinal study exploring the relationship of sleep problems with various parent and child characteristics for 178 children with an ID. The child assessments considered mobility, continence, self-help skills, vision, hearing, academic skills, communication, behaviour problems, and medical conditions. Children with an ID who had sleep problems displayed significantly less use and understanding of communication, poorer academic skills, and poorer self-help skills. They were significantly less established regarding continence; younger children between five to ten years also experienced significantly more sleep problems. Furthermore, children with sleep problems presented with significantly

more behaviour problems than children who did not have sleep problems. Parental assessment involved socio-economic factors, child functioning, behaviour, family environment and relationships, social support, coping, life events, maternal stress, the child's impact upon the family, marital satisfaction, felt needs, and service satisfaction. Parents of children with a sleep problem recorded significantly higher scores on irritability, stress, and measures of extra demands placed on the family as a result of the child's disability. A path analysis showed that the age of the child, level of physical and intellectual impairment, presence of communication and behaviour problems as well as parent stress, accounted for half of the variance within the sleep problem index scores.

2.4 Concluding Comments

Various factors have been considered in relation to children's sleep problems. There appears to be a clear association between daytime behaviour and sleep problems in both TD children and children with an ID. However, this does not indicate the direction of the association. For TD children, temperament and age of the child, as well as the presence of a medical condition or poor health have also been linked to sleep problems. For children with an ID less definitive findings have been obtained.

It is apparent that certain parent factors are also associated with the existence of sleep problems in children. Maternal stress is higher in mothers who have a child with a sleep problem. For parents who have a TD child, poorer maternal attachment, introversion and neuroticism have been linked to sleep problems in the child. However, these parental factors have not yet been examined in relation to sleep problems in children with an ID. One study has reported that some mothers do not

consider their child with an ID to have a sleep problem when one exists. This may be explained by the presence of factors that moderate stress, such as an internal locus of control and perceived control over the sleep problem behaviour.

The above literature demonstrates that sleep problems in children are a complex, multifaceted issue involving characteristics of both the parent and the child. Careful examination of these issues is required as they have important implications for the treatment of child sleep problems.

CHAPTER THREE. TREATMENT OF SLEEP PROBLEMS IN TD CHILDREN AND CHILDREN WITH AN ID

This chapter focuses on the treatment of night settling, night waking, early waking and co-sleeping problems in TD children as well as children with an ID. These sleep problems are frequent, and are associated with various child and parent factors. The types of treatment options are outlined, and studies are presented regarding the efficacy and effectiveness of treatment for sleep problems. The role and importance of parent training is considered in relation to the treatment of night waking, night settling, co-sleeping, and early waking problems. Improvement in the child's daytime behaviour as a result of sleep problem treatment is also discussed. Finally, possible barriers that prevent parents from seeking/obtaining the most appropriate treatment for their child's sleep problem are considered.

3.1 Pharmacological Treatment

The use of pharmacological interventions for the treatment of sleep problems in TD children and children with an ID is a common practice (Durand et al., 1998; Owens et al., 2005; Wiggs & Stores, 1996b). As a result of an increasing awareness of the negative effect that sleep problems can have on children, parents and/or physicians may be more inclined to use or recommend soporifics to treat child sleep problems (Reed & Findling, 2002). While medications are believed to be effective in treating various primary parasomnias such as sleep paralysis, head banging, sleep walking, sleep talking, nightmares, and disorders associated with REM sleep, medication has little part to play in sleep problems related to upper airway obstruction. Furthermore, soporifics are often recommended or used to ameliorate

problems of sleeplessness such as settling, night waking, and early waking disturbances despite a lack of research regarding their effectiveness (Stores, 2003).

An American study by Owens, Rosen, and Mindell (2003) examined the use of non-prescription and prescription medications by community-based paediatricians for children with difficulties in initiating and maintaining sleep. Non-prescription medication was recommended by over 75% of paediatricians while prescription medications were recommended by more than 50% of paediatricians. Insomnia and bedtime struggles or sleep-onset-delay were the most common sleep disorders where non-prescription and prescription medications were recommended. Over-the-counter antihistamines were the most common medication recommended for the child's sleep disorder, followed by combination pain relievers containing a sedating antihistamine, melatonin, and herbal preparations. For prescription medications, alpha-agonists such as clonidine were the most common medication recommended by practitioners followed by antihistamines such as diphenhydramine, and hydroxyzine. Antidepressants (e.g., selective serotonin reuptake inhibitors, and tricyclics), benzodiazepines (such as diazepam and clonazepam), chloral hydrate, hypnotics, antipsychotics, anticonvulsants and barbiturates were also recommended.

Furthermore, the presence of an ID or developmental delay within the child was listed by 45% of paediatricians, and rated as the equal second highest clinical circumstance that led to a pharmacological recommendation for treatment of the sleep disorder. The presence of autism or pervasive developmental disorder within the child was listed by 38% of practitioners and rated as the fourth highest clinical circumstance that led to non-prescription or prescription medication for treatment of the sleep disorder (Owens et al., 2003). This finding is similar to that of Wiggs, and Stores (1996b) who reported that parents who had a child with an ID and a sleep

problem were commonly prescribed medication. Of the 58 parents who had sought treatment for their child's sleep problem, 36% were offered medication, while 27% were offered behavioural advice, 24% were offered a combination of medication and behavioural intervention, and the remaining 13% were offered another form of treatment advice.

In another study Owens (2001) assessed the knowledge and treatment practices of American community-based and academic paediatricians in relation to sleep disorders in children and adolescents. The results showed there are significant gaps in basic knowledge regarding sleep disorders in this population with many paediatricians not adequately screening for sleep problems. This finding was also reported in an Australian study where general practitioners raised sleep problems in only 10.1% of symptomatic children (Blunden et al., 2004). Furthermore, paediatricians have reported low confidence in their ability to identify and treat sleep disorders highlighting a lack of professional education (Owens, 2001). Mindell, Moline, Zendell, Brown, and Fry (1994) evaluated paediatrician training and practice in relation to sleep disorders in children and adolescents. On average, American paediatric residents received a total of 4.8 hours of instruction on sleep disorders. While the majority of paediatricians recommended behavioural interventions, 14.8% reported that they had prescribed medication, and 48.9% stated that they usually or always told parents that their child would outgrow the sleep problem.

3.1.1 Research of Pharmacological Treatment for Sleep Problems in Children

The lack of professional sleep education provided to paediatricians is further exacerbated by the fact that childhood sleep disturbances are one of the most poorly researched areas in paediatric psychopharmacology (Mindell & Owens, 2003). As a

result, a multidisciplinary task force on pharmacotherapy in paediatric sleep medicine has been established in America to educate paediatricians in relation to the diagnosis and management of sleep disorders in children. The taskforce also aims to develop standards of practice for the use of pharmacotherapy, and advocate for further research in this area (Owens et al., 2005). To date there is a paucity of controlled clinical studies to provide professionals with guidelines stipulating the effective and safe use of medication for sleep problems in children. Instead medications are regularly being prescribed to children based on the empirical data obtained from the adult population (Rosen, Owens, Scher, & Glaze, 2002). The American Food and Drug Administration have not approved any medications for the treatment of sleep problems related to difficulty initiating or maintaining sleep. Thus, research needs to evaluate currently used medications (Owens et al., 2005).

Only a small number of studies have considered the use of medication to treat sleep problems in children. Richman (1985) performed a double-blind drug trial of trimeprazine tartrate (Vallergan Forte) for 22 TD children aged 12-24 months with severe waking problems. Results of the drug trial showed that parents reported both improved settling at bedtime and less night waking while their child was on a 30-60 milligram dosage of the drug taken before bedtime. Furthermore, sleep scores reported while the children were on the drug were lower compared to when the children were on placebo. While these differences were significant they were not believed to be clinically striking. No reported effect was found for one third of the children, while the extent of improvement was limited, with children on average still waking nearly four nights a week. Furthermore, follow-up six months after treatment was completed revealed no significant decreases in night waking from baseline scores.

In a similar study Simonoff and Stores (1987) also found trimeprazine tartrate was superior to the placebo in reducing night waking frequency for 20 TD children aged between 12 and 36 months. Using dosages of between 45 and 90 milligrams the reduction in night waking frequency at four week follow up was significantly lower than baseline measures. France, Blampied, and Wilkinson (1991) considered night waking in 30 TD children aged from 7 to 27 months, and reported that 30-milligram dosages of trimeprazine in conjunction with extinction (a behavioural technique, see section 3.3.2) reduced night waking more quickly than placebo and extinction. However, no difference was found between the two groups at the end of treatment and at four-week follow up.

These studies suggest that trimeprazine tartrate may lead to short-term improvement in night settling and night waking problems of TD children. To date, there has been a lack of research to demonstrate the efficacy of the many different types of prescription and non-prescription medications that are often used to treat frequent childhood sleep problems such as night settling and night waking. No clinical pharmacological studies have been conducted for children with an ID who have night settling and/or night waking problems, yet they are more likely to be recommended medication for such sleep problems, presumably because the child has a disability. Professionals are offering such medications without having any clear guidelines regarding proposed drug type, dosage, tolerability, or duration of treatment. A further problem with the use of medication to treat settling and waking problems in children is that the child does not learn to settle and self-soothe at bedtime and upon waking during the night (Stores, 2003). Hence, medication on its own may provide short-term relief only, and its optimal use would be in combination with behavioural methods (France et al., 1996; Owens et al., 2005; Stores, 2003).

The short-term use of medication may reduce bedtime struggles, increase sleep duration, and thus help parents implement behavioural strategies (Mindell & Owens, 2003). Another sedative that is becoming more popular and may be more appealing than other pharmacological agents is the use of melatonin (Sajith & Clarke, 2007).

3.1.2 Melatonin

Melatonin is a serotonin derivative mainly produced in the pineal gland during darkness and is suppressed by exposure to bright light. The suprachiasmatic nucleus regulates secretion of melatonin by relaying light information to the pineal gland (Turk, 2003). Melatonin use promotes sleep onset within approximately 30 minutes and as a result has been used for adult insomnia. Through its action melatonin can shift the sleep phase making it an effective intervention for circadian sleep-wake cycle disorders associated with jet lag, shiftwork, delayed sleep phase syndrome, and mistiming of sleep in people with a visual disability (Stores, 2003). Melatonin is regularly prescribed by clinicians as a sedative for children, however, there are no established guidelines for its use. Furthermore, the side effects and safety of its use, especially in the medium to long-term, are unknown (Bramble & Feehan, 2005; Owens et al., 2005).

Sajith and Clarke (2007) reviewed the use of melatonin to treat sleep problems in children and adults with an ID. They reported that melatonin appears to be free of side effects when used in the short term, although it is unclear whether the initiation of puberty is influenced by melatonin. Furthermore, melatonin may have a contraceptive action for women, and can affect ovarian functioning, while for men concerns have been raised regarding long-term melatonin treatment and sperm quantity and quality. Other side effects reported in a minority of cases have included

paradoxical hyper-excitability, nausea, drowsiness, headaches, bedwetting, irritability, and shivering (Bramble & Feehan, 2005). It has been suggested that melatonin use for children with epilepsy can trigger or negatively influence seizures, however, the majority of studies indicate that it is safe for use in children with epilepsy (Jan & Freeman, 2004). Melatonin has a positive effect on sleep latency and is especially useful for treating settling difficulties, delayed sleep phase syndrome, and free-running circadian rhythms (Sajith & Clarke, 2007).

Dodge and Wilson (2001) explored the safety and efficacy of melatonin in treating 20 children with an ID who had sleep problems. The children in the study were aged between 1-12 years, had a moderate to severe level of ID or had autism, and had previously tried behavioural interventions. All but two children displayed a decrease in the time taken to fall asleep while taking melatonin compared to placebo or baseline, and the parents of 16 children felt that sleep had improved. While melatonin did not have an effect on sleep duration or night waking, such a result was not expected because a short-acting preparation had been used. No significant side effects were reported, however, there was a high drop-out rate.

In a case study design, Camfield, Gordon, Dooley, and Camfield (1996) evaluated the use of melatonin in treating the fragmented sleep of six children with an ID. Each child underwent a 10-week, double-blind trial, however, at the end of treatment no notable differences in the sleep of the children were reported by parents. While these results greatly contrast those of previous studies that have found melatonin to be useful for the majority of children with an ID (Dodge & Wilson, 2001; Jan, Espezel, & Appleton, 1994; Jan et al., 2000), there were a number of limitations with this study. The dose of melatonin was considerably smaller compared to previous studies, and melatonin may have been taken too early (6pm) to

have its desired effect on sleep latency. Furthermore, children took melatonin for a maximum of 2 weeks at a time, when longer time periods may be required in order for it to have an effect (Jan & Freeman, 2004).

Reports to date suggest that melatonin is best for sleep induction, useful for repeated night waking, and least beneficial for early morning waking. Early morning waking may be more difficult to treat with melatonin because its effect typically lasts between six to eight hours, while children require up to twelve hours sleep per night (Jan & Freeman, 2004). A paediatric study has examined the use of melatonin in a controlled slow-release form (Jan et al., 2000). Forty-two children with severe, multiple disabilities who were already taking fast release melatonin participated in the study. The results confirmed that fast release melatonin is best used where the primary sleep complaint is delayed sleep onset, while the controlled release form was more effective for sleep maintenance and even early morning awakenings. In several children, a combination of the fast and controlled release formulations produced the best sleep pattern for the child.

Evidence suggests that melatonin frequently produces marked improvements in chronic sleep disturbances in children with an ID. Furthermore, it appears to be a rapidly acting treatment that is a safe method of ameliorating sleep problems in children with an ID (Turk, 2003). Higher doses of up to 15 mg may be needed for children with more severe disabilities, and those with a profound ID may take weeks or even months to show improved sleep (Jan & Freeman, 2004).

However, certain aspects of many of the studies conducted so far cloud the efficacy of melatonin use for sleep problems in children with an ID. There has been a wide age range for reported cases, many reports have been single case studies, while larger studies have not been controlled. Vague descriptions have been provided in

relation to the sleep disorder being treated, and clear dosage ranges have not been established. Also, most studies have involved children with multiple disabilities, often including blindness, and melatonin has been used in conjunction with behavioural interventions making it difficult to ascertain whether improvements were actually due to melatonin use (Lancioni, O'Reilly, & Basili, 1999, Stores, 2003).

Further research is required in order to overcome the above issues and clarify the efficacy of melatonin for treatment of sleep problems in children with an ID. Melatonin use seems preferable to current, conventional, sedative-hypnotic drugs and may be appropriately considered in a sleep disorder that is likely to respond, and where behavioural treatment (see section 3.3) is not possible or has been adequately but unsuccessfully tried (Stores, 2003). It is still an investigational drug that is considerably new to the area of sleep problems in children with an ID so further investigation of possible short-term and long-term benefits as well as adverse effects is needed (Turk, 2003). While melatonin can be used to treat settling difficulties, it is also used for sleep problems related to the timing of sleep. Sleep problems of this nature are sometimes treated using circadian altering strategies.

3.2 Circadian Altering Strategies

Circadian altering strategies are useful for those sleep-wake disorders where the timing of sleep is inappropriate or irregular. Such circadian altering strategies aim to reset and maintain the appropriate timing of sleep within the individual. There are two main circadian altering methods:

1. Exposure to bright light
2. Chronotherapy.

3.2.1 Light Therapy

Light exposure is one of the strongest, natural entraining influences on the circadian system. Its propensity to cause phase shifts in the sleep-wake schedule has meant that light exposure is considered as a treatment for sleep-wake disorders that are involved with circadian rhythm abnormalities such as jet lag, delayed and advanced sleep phase syndrome, and sleep disturbance associated with shift work (Campbell, 1997). When implementing light therapy it is important to take into consideration the amount and timing of light exposure, including periods of exposure to darkness, as this can greatly influence the success of the treatment (Terman & Terman, 2005).

Short and Carpenter (1998) used light therapy to treat sleep onset and night waking in a 34-year-old man with a profound ID and vision impairment. Light therapy consisted of two hours exposure to natural light on a daily basis. A normal sleep pattern emerged after two weeks of treatment. Smith, Dykens, and Greenberg (1998) also used light therapy for a 6-year-old girl with Smith-Magenis syndrome who displayed sleep problems and behavioural problems during winter. In another study, morning and midday light exposure in conjunction with daytime and bedtime routines was found to be effective in ameliorating sleep problems in 5 out of 14 children with severe brain damage (Guilleminault, Crowe McCann, Quera-Salva, & Cetel, 1993). These sleep improvements were maintained at follow-up several years later.

While these studies suggest that light therapy may be effective in treating sleep problems that are associated with circadian rhythm abnormalities, it is difficult

to interpret the specific effects of this treatment as intervention has also included the use of sleep-wake scheduling or routines (Didden & Sigafoos, 2001).

3.2.2 Chronotherapy

Chronotherapy is used to synchronise the circadian cycle with the daily schedule, and involves systematically delaying bedtime every day until a desirable sleep onset time is achieved. In this way chronotherapy overcomes natural circadian drift that will delay sleep onset. Once sleep occurs at the desired time the new schedule needs to be maintained so the body can reset its internal clock each day in order to uphold a regular sleep-wake cycle (Didden & Sigafoos, 2001; Mindell, 1997).

Chronotherapy is used for circadian sleep-wake disorders such as delayed sleep phase syndrome and irregular sleep patterns (Richdale, 1999). Piazza, Hagopian, Hughes, and Fisher (1998) had success using chronotherapy to treat an 8-year-old girl with a severe ID, autism, and sleep problems that consisted of irregular sleep onset, variable wake times, night waking, early waking, daytime sleep, and short sleep times. An average night sleep of 5.9 hours was recorded during baseline. Treatment consisted of successively delaying bedtime by 2 hours during the initial 8 days, with subsequent delays consisting of 1 hour until the targeted bedtime and wake time were achieved. Using this method, time of sleep onset decreased and average sleep per night increased to 7.9 hours. These changes were maintained at 4-month follow-up, indicating that chronotherapy may be an alternative treatment for correcting irregular sleep-wake cycles where other treatments have failed.

While chronotherapy would be a difficult strategy to implement, effects may be attained within days. To date, this is one of the least used sleep problem treatment

strategies, and further studies are needed in order to replicate results and determine its usefulness across the range of sleep problems in children with an ID (Lancioni et al., 1999).

3.3 Behavioural Interventions

Since many of the extrinsic dyssomnias are behavioural disorders, behavioural intervention is considered an effective treatment for such sleep problems in TD children and children with an ID. These interventions revolve around the belief that parental attention as a result of the child's behaviour serves to maintain the child's sleep problem. For a child with a sleep disturbance, signalling to parents is reinforced by parental stimulation during sleep onset. For the parent, providing inappropriate proximal cues for sleep onset by attending to the child and stopping them from crying is negatively reinforced. As a result, the child is continually reinforced for crying, and parental attention becomes a requirement in order for the child to reinitiate sleep after night wakings. A behaviour trap ensues as the parent attends to the child in order to cease their crying, while the child cries in order to avoid having to fall asleep alone (France & Blampied, 1999).

Parental attempts to withdraw reinforcement for the child's signalling behaviour initially results in an increase in crying and other signalling behaviour from the child. Consequently the parent is likely to continue to attend to the child. This response further strengthens the coercion trap as the child's signalling behaviour is again reinforced, making it more difficult to ameliorate (France & Blampied, 1999). Therefore, behavioural methods that are based on learning theory are used to help break this coercion trap and teach the child to fall asleep on their own (Mindell & Durand, 1993). The interventions used are based on behavioural

principles such as reinforcement, shaping, fading, stimulus control, cueing, and extinction. The types of behavioural interventions will be presented first, followed by a review of their efficacy in treating sleep problems of TD children as well as children with an ID.

3.3.1 Positive bedtime routines

One first-line of treatment for childhood night settling problems has been the introduction of a positive routine specifically created to meet bedtime demands (Ferber, 1985). This technique utilises the behavioural strategies of positive reinforcement, cueing, and stimulus control (Richman, Douglas, Hunt, Lansdown, & Levere, 1985). The bedtime routine typically consists of a series of relaxing activities that help the child associate this time with sleep. The last 30 minutes before sleep are allocated to activities such as dressing for bed, washing, reading, and bidding the child goodnight. The order and timing of activities should remain constant, and events that cause conflict or may interfere with sleep onset should be avoided (Durand, 1998).

3.3.2 Systematic Ignoring

The systematic ignoring approach consists of implementing a bedtime routine, placing the child in bed at the appropriate time, and thereafter not attending to the child unless he/she is ill or in danger (France et al., 1996). This approach utilises the behavioural strategy of extinction, whereby the parental presence and interaction that serve to reward and maintain the sleep problem are removed (Richman et al., 1985). Initial attempts to ignore the child's signalling generally lead to an increase in the frequency and severity of the child's behaviour, otherwise

referred to as the extinction burst. Therefore, a temporary exacerbation in the child's behaviour will occur with the use of this procedure and it is important that parents do not reinforce the undesirable behaviour by attending to the child (Owens, Palermo, & Rosen, 2002).

While systematic ignoring is rapid acting, with improvements seen within three days, parents may find this approach unacceptable due to the distress of leaving their child to cry for long periods of time (France et al., 1996; Wiggs, & France, 2000). Lancioni et al. (1999) state that intense, prolonged distress could have potentially harmful effects on the child. Furthermore, using an approach that is likely to be perceived negatively could also have a detrimental impact on the parents both at a personal and social level.

As a result, three modified versions of the systematic ignoring approach have been developed. They consist of graduated ignoring, ignoring with minimal check, and ignoring with parental presence.

3.3.3 Graduated Ignoring

This approach involves the parent gradually increasing the amount of time spent ignoring the child's bouts of crying at bedtime or upon awakenings (Durand, 1998). Using the graduated ignoring approach requires strong commitment and good organisation over an extended time period. There is also a greater chance for interruption of the program due to unexpected variables such as child illnesses. This approach is believed to be more acceptable to parents compared to the standard systematic ignoring approach (France et al., 1996).

3.3.4 Ignoring with Minimal Check

This procedure is similar to systematic ignoring except that the parent conducts brief checks at regular intervals (i.e., every 5 to 10 minutes) when the child is crying, to provide minimal reassurance. While this procedure may be appealing to parents who want to check in on the child the crying duration is longer. Hence, parents must ensure that they do not increase the intensity of the reassurance they provide over time (France et al., 1996).

3.3.5 Ignoring with Parental Presence

This approach consists of the parent sleeping in the same room as the child but in a separate bed for one week. During this time, the parent is instructed to feign sleep and not have any interaction with the child (France, Blampied, & Henderson, 2003). At the end of the week the parent recommences sleeping in a separate room to the child. This method is particularly useful where parents are concerned about separation anxiety, however, it requires a temporary change to the sleeping arrangement of the parent. Furthermore, some parents may not be able to lie and listen to the child cry without attending (France et al., 1996).

3.3.6 Scheduled Awakenings

This technique is used for night-waking sleep problems and alters sleep staging by waking a child 15 to 30 minutes before they spontaneously wake, and then allowing the child to resettle. The number of pre-emptive awakenings is then gradually reduced until the child sleeps through the night without waking (Owens, France, & Wiggs, 1999; Owens et al., 2002).

3.3.7 Sleep Scheduling

Sleep scheduling utilises the behavioural principle of stimulus control to increase sleep onset at bedtime (Wiggs & France, 2000). It consists of setting fixed times for sleep onset and morning awakening, with sleep outside of the scheduled times prohibited (Didden & Sigafos, 2001).

3.3.8 Faded Bedtime

The faded bedtime procedure consists of setting a late bedtime in order to increase the probability of the child initiating sleep quickly. Provided the child falls asleep within 15 minutes, bedtime is then gradually faded by 30 minutes each night until the desired bedtime is reached. A response cost element can be added in order to increase motivation to fall asleep rapidly. The child is removed from the bed for one hour if not asleep within 15 minutes, and bedtime the next night is set 30 minutes later. Sleep is also scheduled, with the child being awoken at the same time every morning, and sleeping outside of the allocated time is restricted (Piazza, Fisher, & Sherer, 1997).

Using the faded bedtime with response cost procedure is advantageous because it does not lead to an initial increase in the sleep problem behaviour due to the extinction burst, as occurs with extinction procedures. In this way, it also prevents enduring long bouts of crying. However, shortcomings of this procedure include taking several weeks to meet the desired bedtime, and the parent having to remain up late at night with their child (Durand, 1998).

Sleep restriction is a similar approach to faded bedtime and involves limiting the amount of time in bed to the total amount of time asleep. Sleep is restricted to 90% of the hours slept each night and the amount of time asleep is adjusted by 15

minutes for each successful week until the designated sleep schedule is reached (Christodulu & Durand, 2004).

3.3.9 Prevention Through Parent Education

Given the high prevalence rates and persistence of sleep problems in children, early intervention and prevention of such problems through parent education is an extremely important strategy. Strategies that focus on the development of sleep routines, parental handling during sleep initiation, and response to night waking have been used successfully in an educative manner (Kuhn & Elliott, 2003).

3.4 Studies of behavioural intervention efficacy

This section reviews the literature in relation to the treatment of sleep problems in TD children and children with an ID with the use of behavioural intervention. The review will consider group design studies, followed by single case designs. For TD children, a review of behavioural interventions found that 94% of studies reported clinically significant improvements in night settling and night waking problems (Mindell, Kuhn, Lewin, Meltzer, & Sadeh, 2006). Systematic ignoring, graduated ignoring, ignoring with minimal check, ignoring with parent presence, and prevention through parent education are considered well-established interventions reflecting a high degree of clinical certainty. While positive bedtime routines, faded bedtime, and scheduled awakenings are considered probably efficacious interventions indicating a moderate degree of clinical certainty (Kuhn & Elliott, 2003; Morgenthaler et al., 2006).

For children with an ID, sleep intervention literature exploring the impact of sleep problems and successful treatment is lacking. Systematic ignoring and graduated ignoring are considered to be probably efficacious treatments while other behavioural interventions are considered to be experimental (Richdale & Wiggs, 2005).

3.4.1 Group Designs

To date four group design studies have been conducted on the prevention of infant sleep problems through parent education. Wolfson, Lacks, and Futterman (1992) randomly assigned 60 first-time parent couples from childbirth classes to a four-session training group or a control group. Parent training involved two, weekly, prenatal group sessions where procedures were explained to parents. Two post-birth booster sessions were also held to review and reinforce the techniques that had been previously learned. At 6 to 9 weeks of age, infants in the training group had significantly better sleeping patterns than infants in the control group, and parents reported greater parental competence and less awakening and responding to infant signalling. A limitation of this study was that follow-up was conducted when the infants were 16 to 20 weeks old. A longer follow-up period would have given a better account of the importance of the intervention procedure as night waking becomes more prevalent after the age of 6 months.

Adair, Zuckerman, Bauchner, Philipp, and Levenson (1992) used a prospective cohort design with historical controls to evaluate a brief intervention to prevent infant night waking. Intervention occurred at the 4-month visit and outcome was assessed at 9 months. The intervention consisted of an information sheet provided at the 4-month visit, completion of a sleep chart prior to the 6-month visit,

and discussion of the sleep chart with the paediatrician during the 6-month visit. Outcomes of the intervention group were then compared to information previously gathered from the control group of parents at their 9-month visit. Infants in the intervention group woke significantly less, settled easier, and received less parental presence than infants in the control group. While this was not a randomised control study, the two groups were from the same practice and displayed similar demographics. Furthermore, efforts were made to obscure the purpose of the study by including questions about infant feeding habits in the outcome measure.

In a randomised controlled trial Kerr, Jowett, and Smith (1996) evaluated sleep intervention provided to the parents of 3-month old infants, and at 9-months compared their sleep behaviour with a group of control infants. Parents in the intervention group received a home visit to discuss settling methods and the importance of routine. Health education booklets were also provided. Compared to the control group infants in the intervention group displayed significantly less settling difficulties, less night awakenings, and also awoke less often.

Symon, Marley, Martin, and Norman (2005) performed a randomised controlled trial of 268 families to evaluate the impact of a single consultation with a nurse who advised the use of behavioural approaches to improve infant sleep. The control group received usual care while the intervention group attended a consultation when their infant was between 2 to 3 weeks old. They received advice and an information book on normal sleep patterns in infants. At 6 weeks and 12 weeks of age the intervention group displayed a greater mean total hours of sleep, as well as greater hours of night sleep and daytime sleep compared to the control group infants.

Thus research that has been conducted to date on the prevention of sleep problems demonstrates the importance of early parent education. Given that sleep problems in children are a relatively common occurrence and have a tendency to be long lasting, it is imperative that wherever possible such problems are prevented.

Behavioural intervention strategies for sleep problems in children are more frequently used to treat the problem rather than to prevent the problem. Therefore, the majority of behavioural intervention group design studies have focused on the treatment of sleep problems in children.

Adams and Rickert (1989) performed a controlled trial with 36 TD children between the ages of 18 and 48 months. The children were assigned to a positive bedtime routines group, a graduated extinction group, or a control group. At six-week follow-up, children in both the positive routine treatment group and the graduated extinction group displayed a reduction in tantrum activity at bedtime compared to the control group. Furthermore, the use of positive routines led to slightly more rapid improvement, and the parents in this group reported higher marital satisfaction that was attributed to a reduction in stress. Parents in the positive routines group also had fewer questions regarding procedure implementation compared to parents using the graduated extinction approach. Another benefit noted by many parents using the positive routines approach was the opportunity to have positive interactions with their child while eliminating the sleep problem. As a result of the positive bedtime routine, the inappropriate behaviour displayed by children at bedtime had been replaced with a new desirable behaviour.

Reid, Walter, and O'Leary (1999) directly compared the use of standard systematic ignoring to graduated systematic ignoring for TD children with sleep problems. In this study 49 children between the ages of 16 to 48 months were

randomly assigned to either the standard systematic ignoring group, the graduated systematic ignoring group, or to a wait-list control group. In conjunction with the ignoring strategy, parents were told to use praise and give small rewards the morning after a successful night. Distraction strategies, and parent turn-taking to manage bedtime behaviour were also suggested in order to help parents resist giving into the child's crying. The treatment groups were equally effective and significantly better compared to the wait list control group, with improvements maintained at two-month follow-up. No difference was reported in the dropout rates of parents between the two approaches. Parents who dropped out of the study had younger children, expected to have more difficulty complying with the treatment, and reported being unable to ignore their child's cries regardless of the type of extinction procedure used.

Furthermore, Reid et al. (1999) reported that parents found the graduated ignoring procedure was easier to implement, especially during night waking. Maternal characteristics were associated with treatment compliance and better outcome in the standard ignoring treatment approach but not the graduated approach. Less stress within the parental role was associated with treatment compliance, while treatment outcome was better for mothers who were less depressed, less distressed about parenting, and who made fewer disciplinary mistakes. This result led the authors to suggest that maternal characteristics were useful in deciding upon recommendation of the standard ignoring procedure.

Using the standard systematic ignoring procedure in conjunction with a bedtime routine, Seymour, Bayfield, Brock, and During (1983) reported that 95% of parents in their study were able to implement this procedure in order to manage night waking. They reported on 208 children aged from birth up to six years who were

referred to a night waking program during a two-year period. Parents were seen either individually or in small groups and were given written instructions about the program. Phone calls were then made for the first three days and a second interview occurred a week later whereby any remaining problems were discussed. Two more phone calls were conducted over the next three weeks and then follow-up calls were made at one, three, and six-month intervals. The program produced rapid and sustained change in the vast majority of cases, leading the authors to declare that, given adequate assurance and ongoing support, parents are able to ignore their child's crying.

In another group study using the standard systematic ignoring approach, Seymour, Brock, During, and Poole (1989) compared the therapist-guided program with a group that received written information only, and a wait-list control group. Forty-five children aged 9 months to 5 years were randomly assigned to one of the three groups. Parents in the standard therapist-guided group received the same program as that described previously (Seymour et al., 1983), while the written information group were given the parent guide to read and any questions were answered. These parents received a total staff attention time of up to 10 minutes, and no telephone contact was provided. The therapist-guided group and the written information group had significant improvement compared to the control group, although the therapist-guided program led to more rapid improvements.

In contrast, a controlled trial conducted by Weir and Dinnick (1988) where health visitors acted as therapists, found no difference between behavioural intervention and the control procedure. Fifty-one children aged between 4 months and 4.5 years who displayed night settling or night waking problems were non-randomly assigned to one of the two groups based on geographical location. The

behavioural intervention focused on four, central techniques that consisted of extinction, reinforcement, shaping, and cueing with emphasis placed on the health visitor negotiating a course of action based on these four principles. The control group health visitors were instructed to give advice or make referrals as was their usual practice. Both groups showed improvement at six-month follow-up with the behavioural intervention group displaying a slight, but non-significant trend towards a higher rate of improvement. Possible reasons for these findings that were suggested included that health visitors may have been inadequately trained, that a high spontaneous remission rate and small sample size made it difficult to identify a treatment effect, or that improvement was due to a non-specific effect common to the experimental and control groups.

Pritchard and Appleton (1988) also investigated the importance of therapist contact with a modified extinction approach. Graduated systematic ignoring with constant interval (minimal) checks was used in conjunction with a bedtime routine to improve the night settling and night waking problems of 31 TD children aged 9 to 42 months. The families were randomly allocated to one of two groups where therapist contact varied. One group was visited every three days while the other group did not receive a visit until they had implemented the program for two weeks. A rapid improvement in the number of night wakings, and the time taken to settle to sleep were observed, with the improvements maintained at 3-month follow-up. Intensity of therapist contact did not have any impact upon treatment effectiveness, however, knowing that the therapist would be visiting again appeared to be an important factor in maintaining program adherence.

Hiscock and Wake (2002) conducted a randomised controlled trial of behavioural intervention for the sleep problems of 156 infants aged 6 to 12 months.

The main intervention used was graduated ignoring, while parents in the control group were mailed a sheet that explained normal infant sleep patterns. At two months significantly more sleep problems had been resolved in the behavioural intervention group compared to the control group, however, at four months this finding was no longer significant. A possible explanation for this lack of significance at four months is that some parents in the intervention group ceased using the behavioural strategies, or that there may have been a tendency for sleep problems to resolve naturally over time. Although a more likely explanation is that parents in the control group had sought sleep intervention from somewhere else. Significantly more control group parents had sought extra help (30% compared to 12% in the behavioural intervention group) and mothers within the control group who sought extra help reported a higher rate of amelioration of their child's sleep problem (56% compared to 43%).

Sadeh (1994) evaluated modified extinction, randomly allocating 50 children aged between 9 and 24 months to one of two intervention methods. One group were instructed to use ignoring with minimal checks, while the other group used ignoring with parental presence. No significant differences were reported between the two intervention methods, with 60% of children showing significant improvement.

To date, three group design behavioural intervention studies have been conducted for sleep problems in children with an ID. In a recent study Montgomery, Stores, and Wiggs (2004) evaluated the efficacy of a media based behavioural treatment for sleep problems in children with an ID. In a randomised controlled trial participants were allocated to either a brief booklet treatment, a conventional face-to-face treatment or a crossover control group where there was no intervention for six weeks, and then random allocation into an active treatment group. The treatment

approach was entirely behavioural and included information regarding normal sleep, introduction to behavioural techniques in general, monitoring behaviour, good sleep habits, and specific techniques for changing undesirable behaviour (graduated ignoring). Irrespective of delivery method significant improvements were made compared to results for children in the control group, with 68% of parents satisfied with the booklet treatment compared to 75% treatment satisfaction for the face-to-face group. These improvements were maintained at six-month follow-up and suggest that brief delivery via a booklet for behavioural treatment of sleep problems in children with an ID is as effective as face-to-face treatment.

In an uncontrolled study, Bramble (1996, 1997) demonstrated the effectiveness of the systematic ignoring procedure for sleep problems in children with an ID. The intervention was carried out on 15 children with a severe ID who displayed relentless, lifelong night settling and night waking. Intervention consisted of a single session (with further phone contact) that involved setting regular bed times and waking times, and implementing a positive bedtime routine. Systematic ignoring involved providing physical assistance with minimal affect for children who left the bedroom and refused to return, and a morning reward was given after improved night time behaviour. Parental ratings of their child's sleep problem severity decreased from 8 out of 10 at baseline to 2.9 out of 10 at 18-month follow-up, with no deterioration to pre-treatment levels. Furthermore, the use of systematic ignoring was well tolerated by these parents, with high satisfaction ratings reported.

In a small, uncontrolled group design, Piazza et al. (1997) compared scheduled bedtime with faded bedtime and response cost. Fourteen children with an ID who had early waking, night waking, or settling problems, and who were inpatients in a severe behaviour problem unit, were randomly assigned to the

bedtime scheduling group or the faded bedtime with response cost group. While mean hours of disturbed sleep had improved in the group of children who received the bedtime scheduling treatment, the faded bedtime with response cost group showed a significantly greater reduction in disturbed sleep. Thus, bedtime scheduling on its own may lead to slight improvements in sleep problems for children with an ID, however, it seems that it is better used in conjunction with other behavioural interventions, such as the faded bedtime procedure.

3.4.2 Single case designs

In a multiple baseline design Mindell and Durand (1993) used graduated, systematic ignoring in conjunction with a set bedtime and a positive bedtime routine to significantly reduce both bedtime disturbances and night wakings for six TD children aged between 18 to 52 months. Treatment instituted at bedtime was effective in treating both bedtime and night waking problems.

Using a multiple baseline design, the effectiveness of systematic ignoring in treating night settling, night waking, and co-sleeping problems in five children with autism and six children with fragile-X syndrome has also been demonstrated (Weiskop, 2001; Weiskop, Richdale, & Matthews, 2005). Intervention consisted of conducting a functional assessment of the problematic sleep behaviour, teaching basic principles of learning theory, the establishment of bedtime routines, positive consequences for compliance of the bedtime routine, instruction giving, partner support strategies, and extinction/systematic ignoring techniques. The therapist had weekly telephone contact with parents that increased to daily contact during the first few nights when the extinction procedure was implemented. For one child, sleep behaviour improved as a result of instituting a more appropriate bedtime as well as a

bedtime routine, and extinction was therefore not introduced. For the majority of other children in the study sleep improvement did not occur until systematic ignoring was implemented. High social validity was reported, and clinically significant outcomes were maintained at 3-month and 12-month follow-up.

Thackeray and Richdale (2002) treated the sleep problems of three children with an ID aged 5 to 10 years. Before intervention, all three children required a parent to initiate sleep, two of the children presented with co-sleeping problems, and two of the children had night waking difficulties. In a multiple baseline study sleep intervention consisted of four sessions that involved educating parents about reinforcement of behaviour, instruction giving, bedtime routines, partner support strategies, and the use of standard extinction. Parents also received telephone support when implementing the extinction procedure. Using sleep diaries and actigraphy, improvements in sleep length, sleep latency, and morning wake time were reported. Also, the children were initiating sleep independently. These results were maintained at three-month follow-up, with all families recording strong approval ratings of the treatment techniques used.

Didden, Curfs, van Driel, and de Moor (2002) also used systematic ignoring to treat chronic sleep problems of three children and one adult with an ID. In a multiple baseline design the extinction procedure was effective in reducing disruptive sleep behaviours and establishing normal sleep patterns, with effects maintained at 6-month follow-up. The parents in this study initially found it difficult to implement the systematic ignoring procedure, citing concerns that it would cause their child to feel rejected and afraid. However, after such concerns were allayed the parents found the extinction procedure to be both effective and acceptable. To help

with the implementation of this technique, the researchers suggested daily contact by telephone between the parent and the therapist.

Durand et al. (1996) also used a bedtime routine as well as graduated, systematic ignoring to improve the sleep problems of two children with an ID who exhibited bedtime problems, and two children with an ID who had night waking problems. This multiple baseline across subjects design consisted of a functional assessment to determine the factors that maintained the sleep problem for each child. Improvements were maintained at six-month follow up, and the parents found short delay intervals of the graduated ignoring procedure easy to tolerate.

Ashbaugh and Peck (1998) treated multiple sleep problems of a two-year-old TD child using the faded bedtime with response cost protocol. A significant improvement in sleep disturbance was shown with the onset of the faded bedtime intervention. When baseline conditions were reinstated, the child's sleep disturbance increased. Treatment was reinstituted and the child's disturbed sleep gradually decreased again.

The faded bedtime with response cost procedure has also been used effectively for sleep problems of children with an ID. Piazza, and Fisher (1991) treated three children with a profound ID aged between 3 and 13 years, and an adolescent with a profound ID aged 19 years. Three of the four participants displayed extremely disruptive sleep problems and were treated as inpatients in a severe behaviour problem unit. The fourth child was treated as an outpatient. Children were observed at 30-minute intervals and scored as in bed or out of bed, and awake or asleep. The children's night time sleep increased, while night wakings decreased as a result of treatment.

More recently, sleep restriction has been used to treat sleep problems in children with an ID. Durand and Christodulu (2004) evaluated the effectiveness of the sleep restriction for two children with an ID who displayed bedtime and night waking sleep problems. The children were both four-years-old, and previous treatment attempts using extinction had been unsuccessful. The sleep restriction intervention was effective, ameliorating the sleep problems of both children, and parents reported that the treatment was easy and practical to implement. In a second multiple baseline study, sleep restriction and bedtime routines were used to treat bedtime disturbances and night waking in four children with an ID who were aged from 2.6 years to 5.9 years (Christodulu & Durand, 2004). For one child the bedtime routine alone was sufficient to resolve the child's sleep problem, while for the remaining three children the complete intervention was shown to be successful, with improvement maintained at one-month follow up.

3.4.3 Conclusions Regarding Behavioural Interventions

The literature presented suggests that behavioural interventions are useful in treating a number of sleep problems in TD children and children with an ID, specifically night settling, night waking and co-sleeping problems. Based on the criteria for empirically validated psychological interventions systematic ignoring, graduated ignoring, and prevention through parent education are considered well-established treatments, while scheduled awakenings, faded bedtime, and positive routines are considered probably efficacious treatments (Kuhn & Elliott, 2003; Mindell et al., 2006).

For children with an ID, the use of systematic ignoring is considered a probably efficacious treatment, as is graduated systematic ignoring. The remaining

behavioural treatments are promising but are still considered to be experimental (Richdale & Wiggs, 2005). Although there are some studies that use a multiple baseline design or a randomised controlled trial the majority of studies have been uncontrolled case reports. Studies have also been lacking in regards to homogeneity of participants making it impossible to investigate effectiveness of behavioural intervention across different disabilities (Wiggs & France, 2000). Thus, more work is required in order to ascertain the true efficacy of behavioural interventions for sleep problems, especially for children with an ID.

In evaluating behavioural intervention, some studies have considered whether or not sleep improvement has had a positive effect for other areas of functioning for the child and/or the child's family. One area of particular interest relates to the daytime behaviour of the child.

3.5 Generalisation of Behavioural Strategies

Generalisation relates to the implementation of parenting skills occurring across conditions that are different to the training environment. This may include different circumstances such as a change in settings, different types of behaviours, applying parenting skills to other children, and continued implementation of skills over time after parent training has been withdrawn (Sanders & Dadds, 1993; Stokes & Baer, 1977).

The link that has been established between the presence of sleep problems and the occurrence of daytime behaviour problems in TD children and children with an ID demonstrates the importance of generalisation in parent training (Gregory & O'Connor, 2002; Quine, 1991). A parent who tried behavioural intervention to ameliorate their child's sleep problem could benefit further by also applying the

strategies learned to their child's difficult daytime behaviour. Only a small number of studies have considered this issue in the literature on sleep problems in children.

Minde et al. (1994) examined the effect that a specific, dynamically oriented behaviour approach to sleep management had on daytime behaviour of TD children. Twenty-eight children with serious sleep problems were compared to 30 matched control children. Children in the sleep problem group showed significant improvements in their sleep, as well as in their daytime behaviour, and in feeding interactions with mothers. However, behaviours of the mother showed little change, indicating that generalisation of the specific behavioural principles did not occur. The researchers proposed one possible explanation for this, that it was not the mothers, but the fathers who carried out the actual sleep intervention, and thus, the fathers may have generalised the behavioural principles and instigated changes in daytime behaviour.

Bramble (1997) used systematic ignoring to treat chronic night settling and night waking problems of 15 children with an ID, with a significant decrease in child behaviour problems also reported by mothers. In contrast, Wiggs and Stores (1999) performed a randomised controlled trial of behavioural interventions for sleep problems in children with an ID and challenging behaviour. The successful intervention did not appear to be associated with any change in the daytime behaviour of the children. As a result they suggested that marked improvements in children's behaviour after successful intervention for sleep problems might have been overestimated in previous literature.

Thackeray and Richdale (2002) explored the link between sleep problems and daytime behaviour problems. In a multiple baseline study standard extinction was used to successfully treat settling, co-sleeping, or night waking problems,

subjective and objective behaviour measures were obtained in the school setting. However results obtained for daytime behaviour were inconsistent and did not establish whether behaviour change occurred reliably with sleep intervention.

Weiskop (2001) developed a parent-training program based on behavioural principles in order to ameliorate sleep problems in children with autism or fragile X (Weiskop et al., 2005). The intervention was effective for reducing night settling, co-sleeping and night waking problems, however, no clinically significant changes in daytime behaviour were obtained. Daytime observations of mother-child interactions revealed that generalisation of parent skills across setting and child behaviour did not occur. Possible reasons for this lack of generalisation include that no attempt was made to train a variety of exemplars (only sleep exemplars were used) and training was very specific.

Given the association between sleep problems and behavioural problems in TD children and children with an ID, one would expect that treatment of the sleep problem would result in concomitant improvement in child daytime behaviour. However, the small number of studies that have examined this issue to date have not indicated this, and further research on this topic is required. As the sleep problems are of a behavioural nature the intervention strategies used are also applicable for the management of daytime behaviour problems. However, parents do not appear to generalise the sleep intervention strategies across behaviours. As outlined in Chapter 2, sleep problems in children are also related with various parent factors. Therefore, it is important to assess whether parents report associated improvement with successful treatment of their child's sleep problem.

3.6 Effect of Sleep Intervention on Parents

For TD children successful behavioural intervention for sleep problems has been shown to have a positive effect for parents. Upon treating children's sleep problems, parents have reported concomitant improvements in their own sleep, as well as increased marital and family satisfaction, and decreased stress (Adams & Rickert, 1989; Mindell & Durand, 1993). Behavioural interventions for sleep problems have also been associated with positive improvements in parental mental status, as well as perceived control over the sleep problem and efficacy in its management (Pritchard & Appleton, 1988; Wolfson et al., 1992).

Studies of this nature are scarce regarding sleep problems in children with an ID. In a randomised controlled trial of behavioural intervention for sleep problems in children with an ID, mothers in the intervention group reported increased sleep time (Wiggs & Stores, 1998a). Furthermore, a clinically significant reduction in stress was obtained for mothers in the intervention group compared to the control group. Interestingly, maternal perceived control over the child's sleep improved in both the treatment and the control group, as did sleep satisfaction ratings, daytime sleepiness, and ratings of the child's sleep. Positive effects in the fathers were limited to increased ratings of satisfaction for their own sleep as well as the sleep of their child (Wiggs & Stores, 2001a). Bramble (1997) has also reported significant improvements in maternal stress and maternal sleep quality with the treatment of the child's sleep problem. However, Weiskop (2001) did not report a significant reduction in parent stress following a reduction in child sleep problems.

Thus treatment of the child's sleep problem using behavioural intervention may have more wide ranging effects such as improvements in maternal stress, parental sleep, and maternal perceived control and locus of control. While further

studies are required to support these findings, this does lend additional support to the use of behavioural intervention for the treatment of sleep problems for TD children as well as children with an ID. However, it appears that the majority of parents who have a child with a settling, co-sleeping, or night waking problem are not obtaining the appropriate treatment for such sleep problems.

3.7 Barriers to Obtaining Appropriate Sleep Intervention

While sleep problems in children with an ID are often treatable, it appears that a number of factors currently prevent parents from gaining access to such interventions. Parents may not be aware of a sleep problem, may not care, may attribute behaviour related to the sleep problem to other causes, may believe that the problem is permanent and cannot be treated, may consider the problem to be the result of the child's medical condition, or may believe that the problem is part of the child's disability (Bramble 1996; Robinson & Richdale, 2004; Stores, 2001a).

Furthermore, many parents do not seek treatment for their child's sleep problem. Wiggs and Stores (1996b) reported that only 47% of parents who had a child with an ID and a sleep problem had received advice or treatment for the problem. Robinson and Richdale (2004) reported a similar rate of parents seeking treatment for their child's sleep problem, while Didden, Korzilius, et al. (2002) reported that only 19% of their parents had been given advice about their child's sleep problem. Also, it seems that many parents do not want help to treat their child's sleep problem. Wiggs and Stores (1996b) revealed that only 55% of parents in their study actually wanted help, while Bartlett et al. (1985) found that more than half of the parents of children with an ID who presented with severe sleep problems refused an offer of treatment. A possible explanation for these findings is that many

parents who have a child with an ID do not perceive their child as having a sleep problem. This has been reported in studies for TD children as well as children with an ID (Atkinson et al., 1995; Bartlett et al., 1985; Scott & Richards, 1988). Wiggs and Stores (1996a) found that 17 out of 92 parents failed to identify that their child had a severe sleep problem. Other common explanations for not seeking treatment have included parental views that the child obtains enough sleep, treatment is unnecessary, or that the parents could rectify the problems themselves (Robinson & Richdale, 2004).

This issue is further exacerbated because professionals are unlikely to address sleep problems (Bartlett et al., 1985). Chervin, Archbold, Panahi, and Pituch (2001) reviewed medical records of 103 TD children with prominent symptoms of chronic sleep disorders. Findings revealed that US paediatricians discussed only 16 of the 103 sleep problems, and effectively treated just 3. Furthermore, Blunden et al. (2004) reported that chronic sleep problems were seldom raised by Australian parents during medical consultation. Communication problems between referrers and families regarding treatment procedures, and a lack of suitably qualified or confident health professionals to implement interventions are issues that also prevent proper treatment of sleep problems for children (Stores & Wiggs, 1998). Even when parents are provided with behavioural intervention, the most effective form of treatment for many common childhood sleep problems, the advice given to some parents has been inappropriate or incorrect (Wiggs & Stores, 1996b). Consequently, Stores and Wiggs (1998) state that improvements in education and training are required in order to provide adequate services regarding sleep problems in TD children as well as children with an ID.

3.8 Conclusions

Night settling, night waking, and co-sleeping problems in children are often long lasting and require appropriate intervention from professionals. The most common form of treatment offered to parents is medication, especially when the child has an ID. However, the use of medication to treat such sleep problems has not been well studied, and results suggest that it is best used in conjunction with behavioural intervention, or to provide short-term relief. Melatonin is an investigational drug that has been used to improve the sleep-wake cycle of children with an ID or multiple disabilities. It has shown good results and may be considered when the child displays severe sleep problems and where behavioural treatment is not possible or has been unsuccessful.

Behavioural intervention strategies that focus on developing appropriate sleep behaviour appear to be the most effective form of treatment for such problems. Specifically, techniques utilising the principle of extinction have yielded the best results and have been classified a well-established treatment for TD children. Some parents may have concerns in using rapid extinction as it may mean having to listen to the child cry for long periods of time. Giving a clear rationale and explanation of the procedure, as well as providing (or offering) ongoing support can increase the acceptability of this approach, and many parents have rated this intervention highly. However, graduated ignoring is also effective, and parents have had success using this approach including further modifications such as minimal check or parental presence. Positive bedtime routines, scheduled awakenings, sleep scheduling, and faded bedtime have also been used successfully, although they are not as well supported as extinction.

Another well-established treatment for TD infants is the use of parent education in order to prevent the occurrence of night settling, night waking and co-sleeping problems. A study of this nature has not been conducted for children with an ID and is definitely needed given the high prevalence rate and persistence of such sleep problems.

In addition, further studies are required in order to demonstrate the efficacy of behavioural intervention, especially in relation to sleep problem treatment in children with an ID where studies are lacking. Another problem is that many of the studies to date have not adequately described the methods and approaches that have been used in training parents to ameliorate their child's sleep problem. Also the issue of generalisation to daytime behaviour problems of the child requires further exploration, especially since a link between the co-occurrence of sleep problems and challenging daytime behaviour has been established.

Unfortunately, in the community behavioural intervention is not the first choice of treatment for sleep problems in children with an ID. Of further concern is the fact that sleep problems in children with an ID appear to be a topic of neglect by both parents and professionals alike. Many parents do not recognise their child as having a sleep problem, and many do not seek or want treatment for this problem; professionals seem to seldom address the issue of sleep problems, and often offer treatment that lacks empirical support.

CHAPTER 4. STUDY 1: PARENT PERCEPTIONS OF SLEEP PROBLEMS AND TREATMENT EFFECTIVENESS IN CHILDREN WITH AN ID

4.1 Study Rationale, Aims, and Hypotheses

Research has shown that night waking, night settling, early morning waking, and co-sleeping occur at significantly higher rates in children with an ID as opposed to TD children (Quine, 2001). While rates have varied across sleep problem studies for children with an ID, prevalence rates of greater than 50% have been obtained (Bartlett et al., 1985; Piazza et al., 1996; Quine, 1991).

Despite the common prevalence of these sleep problems for children with an ID many parents do not seek treatment (Didden et al., 2002; Wiggs & Stores, 1996b). Furthermore, research conducted on sleep problems in TD children and children with an ID have reported that some parents do not recognise their child has a sleep problem (Atkinson et al., 1995; Bartlett et al., 1985; Scott & Richards, 1988; Wiggs & Stores, 1996b).

Pharmacological intervention is the most common treatment for sleep problems in TD children and children with an ID, however, this only provides short-term relief and is best used in combination with behavioural intervention (France et al., 1996; Stores, 2003). Research conducted on the treatment of sleep problems in children with an ID using behavioural intervention is promising, and has been rated highly by parents (Bramble, 1996; Richdale & Wiggs, 2005; Wiggs & Stores, 1996b).

Thus, the aims of this study were to:

1. Assess parental perceptions of their child's sleep, including the presence of any sleep difficulties, and whether or not the parent considered their child with an ID to have a sleep problem.
2. Examine whether treatment was sought for the sleep problem, the type of treatment sought, and parents' perception of treatment effectiveness

It was hypothesised that:

1. Between 40-50% of parents would consider their child to have a sleep problem
2. Approximately 20% of parents who reported their child as displaying a sleep difficulty would not perceive their child to have a sleep problem.
3. Of the parents who considered their child to have a sleep problem only 50% would have sought treatment for the problem.
4. Where treatment for the sleep problem had been sought, behavioural interventions would be rated as the most effective.

4.2 Method

4.2.1 Participants

Parents and carers of children from six special schools (children with an IQ between the range of 50-70), five special developmental schools (Children with an IQ less than 50), the Cerebral Palsy Association, Interchange (disabilities service), and one early intervention centre from suburban/metropolitan Melbourne participated in this study in 2001. Two participants became involved in the study independently. Participants were recruited by approaching schools within the state of Victoria. In total, twenty-three special schools, special developmental schools, and

one early intervention centre were approached from July to November of 2001 to recruit parents for the study. One of the special schools approached was located in rural Victoria, while the others were all located in suburban or metropolitan Melbourne. Twelve (50%) of the schools (including the early intervention centre) that were approached agreed to be involved in the study. Four schools chose not to participate as they were already involved in other research projects, while two schools did not participate because they thought that their parents would be reluctant to be involved in the research. Another school chose not to participate due to the high severity of disabilities that the children within their school presented with, and the difficulties this placed on the parents. Five schools that declined to participate in the study did not provide an explanation for their lack of involvement. The two other disability services (The Cerebral Palsy Association, and Interchange) heard about the study, contacted the researcher, and then encouraged their parents/carers to participate.

In total, 809 questionnaires were distributed and 243 (30%) were completed and returned. The return rates from the individual schools varied markedly, ranging from 15.8% to 53.8%.

4.2.2 Materials

The materials consisted of a plain language statement (Appendix A) and a sleep questionnaire. A similar study that had been conducted earlier produced a 31% response rate (Robinson & Richdale, 2004). A higher response rate was desirable in the current study both for statistical reasons, and to maximise recruitment for Study 2. Therefore, in an attempt to increase the reply rate the sleep questionnaire used was a modified version of a two-page sleep-screening questionnaire (Polimeni, Richdale,

& Francis, 2005) (Appendix B). It was anticipated that a considerably shorter questionnaire to the one used in the 2004 study would encourage more families to participate.

The sleep-screening questionnaire contained 15 questions designed to elicit basic information on the presence, type, and treatment of sleep problems in children with an ID. The first six questions consisted of background information relating to the child's age, diagnosis, and medical condition. The next four questions concerned the child's sleep behaviour. Parents noted their child's average sleep length per night (hours), and indicated whether their child displayed problems (settling, early morning waking, night waking, or other sleep difficulties). Where other sleep difficulties were indicated parents were asked to describe the nature of the sleep problem. The child's sleep behaviour or group of sleep behaviours were then given a severity rating (mild, moderate, or severe). Parents also answered whether or not their child's sleep behaviour disturbed their own sleep, and if they considered their child to have a sleep problem.

The next four questions were directly related to the child's sleep problem. They considered the duration of the sleep problem, whether a specific sleep disorder diagnosis had been given, and whether the parent had sought any treatment for the child's sleep problem. Parents who had sought treatment identified the type of treatment, and then reported how successful this treatment had been on a 7 centimetre, visual-analogue scale with extreme statements anchoring each end. Parents who did not think their child had a sleep problem did not complete this section of the survey. All parents were directed to the final question asking whether or not they were interested in participation in a following study at a later date (Study 2). This question clearly specified that families of children with and without sleep

problems were required for the next stage of the study. Those parents who were interested in further participation completed their contact details.

4.2.3 Procedure

The RMIT University Human Research Ethics Committee approved the study (Appendix C), and the Department of Education (Victoria) gave its approval to obtain participants through schools (Appendix D).

For nine schools and the one early intervention centre, the questionnaires were sent home with the school newsletter. The newsletter also contained a note from the principal supporting the research. The schools were also asked to place a reminder note in the newsletter one to two weeks following the distribution of the sleep questionnaire. The questionnaires were completed and returned to the child's school where they were later collected.

For two of the schools, as well as the Cerebral Palsy Association and Interchange, a note was placed in the newsletter outlining the nature of the research. Persons interested in participating then contacted the researcher independently and the questionnaire was distributed and returned via the mail.

4.2.4 Data Analysis

Data were analysed quantitatively using version the Statistical Package for the Social Sciences (SPSS) version 10.0. Specific analyses involved tests of difference for two sample designs using the independent *t*-test, and tests of association using the chi-square test. Where independent *t*-tests were conducted, a Levene test for the assumption of homogeneity of variance was carried out. However, to avoid repetition in the results section, the Levene test statistic will only

be reported and referred to where results have been based on unequal (Levene's $p < .05$) variance.

4.3 Results

4.3.1 Background Information

One hundred and ninety-six (80.7%) of the questionnaires were completed by the child's mother, while 15 (6.2%) were completed by fathers, and a further 11 (4.5%) were completed by parents who did not specify their gender. Five (2.1%) of the questionnaires were completed by carers, three (1.2%) by foster parents, six (2.4%) were completed by other family members, and seven (2.9%) participants did not state their relationship to the child. The children were aged from 3.1 to 18.7 years ($M = 10.6$ years, $SD = 4.1$) while age was not provided for 6 children. One hundred and sixty-six (68.6%) of the children were male, 73 (31.4%) were female, while gender was not reported for 4 of the children.

A range of diagnoses were reported by parents: 107 (44%) children had autism or a pervasive developmental disorder, 69 (28.4%) children had an ID of unknown aetiology, 29 (11.9%) had Down's syndrome, 13 (5.3%) had cerebral palsy, 3 (1.2%) children had both a pervasive developmental disorder and cerebral palsy, and 22 (9.1%) had another diagnosis associated with ID (Table 4.1).

Epilepsy was the most frequently reported medical condition, occurring in 49 (20.2%) children, while 25 (10.3%) had asthma, 12 (4.9%) had Attention Deficit Hyperactivity Disorder (ADHD), and 26 (10.7%) had a range of other medical conditions (Table 4.2). Parents reported that 106 (44%, $N = 241$) children were currently on some form of medication. Forty-two (17.3%) children were taking anti-convulsant medication for epilepsy, 12 (4.9%) were taking central nervous

stimulants (8 for ADHD, 4 for attention/hyperactivity but children did not have a reported diagnosis of ADHD), and 11 (4.5%) were taking anti-psychotic medication for behavioural problems. A further 11 (4.5%) children were taking respiratory inhalants (10 for asthma, 1 for rhinitis), while 4 (1.6%) children were taking antidepressant medication (3 for behaviour, 1 for another condition). Three children (1.2%) were taking antibiotics for infections, and the remaining 40 (16.5%) children were taking some other form of medications (4 for sleep problems, 4 for behavioural problems, 3 for infections, and 29 for other medical conditions). A list of all medications taken by participants, their class, purpose, and side effects upon sleep is contained in Appendix E

Table 4.1. The Types and Frequencies of Medical Conditions Associated with ID in Study 1 Participants

Type of Medical Condition (<i>n</i> = 22)	Total
Cridu Chat Syndrome	2
Undiagnosed Syndrome*	2
Prader Willi Syndrome	2
Pierre Robin Syndrome	1
18q Syndrome	1
Chromosome Abnormality 8q	1
Global Disabilities (Cortical Dyspraxia)	1
Neuro-Fibromatosis	1
Severe Physical Disabilities*	1
Dyspraxia and Brain Damage	1
Velo-Cardio-Facial Syndrome	1
Sturge-Weber Syndrome	1
Metabolic Disorder: Neurodegenerative/Osteodegenerative	1
Rubella	1
Chromosome Abnormality/Deletion 4q	1
Peroxisomal Disorder	1
Fragile X	1
Chromosomal	1
Goldenhaar's Syndrome	1

* Type of medical condition based on parent responses. All children were attending a SS, SDS, or early intervention and would therefore have a developmental delay or an ID.

Table 4.2. The Types and Frequencies of Other Diagnosed Medical Conditions for Study 1 Participants

Type of Medical Condition (<i>n</i> = 26)	Total
Hearing Loss	3
Heart Murmur	2
Hearing and Vision Impaired	2
Multiple Food Allergies	1
Under-active Thyroid and Heart Condition	1
Eczema	1
Diabetes	1
Toxic to Gluten-casein	1
Undiagnosed Apnoea	1
Heart Condition	1
Food Intolerance, Irritable Bowel, Eczema, Allergic Rhinitis	1
Narrow Valve to Heart	1
Chronic Arthritis	1
Renal Transplant	1
Visual Problems	1
Visual Impairment and Undiagnosed Apnoea	1
Retinal Dystrophy	1
Heart Valve	1
Haemolytic Anaemia, Growth Failure, and Splenectomy	1
Hirschsprung's Disease	1
Spectrum of Allergies	1
Overactive Thyroid	1

4.3.2 Sleep Characteristics

Overall, 150 (62.8%, *N* = 239) parents rated their child as displaying some type of problematic sleep behaviour (Table 4.3), and 107 (45.1%, *N* = 237) of the parents rated their sleep as being disrupted due to their child's sleep. Nevertheless, 65 (27.1%, *N* = 240) parents reported that they thought their child had a sleep problem.

Early waking and night waking were the most common types of problematic sleep behaviours, followed by night settling behaviours, and then other types of problematic sleep. The presence of two or more of the above sleep behaviours was common. Ninety-two (62.2%) parents rated their child's problematic sleep behaviour

as mild, 48 (32.4%) rated it as moderate, and 8 (5.4%) considered it to be severe ($N = 148$).

Table 4.3. Types of Child Sleep Disturbance and Frequency as Reported by Parents

Presence of Sleep Disturbance ($n = 239$)	Total	%
Type of Sleep Disturbance ($n = 150$)		
Early Morning Waking	84	35.1
Waking During the Night	84	35.1
Problems Settling to Sleep	62	25.9
Other	11	4.6
Other Sleep Disturbance Reported		
Trouble Waking in the Morning	2	0.8
Tosses and Turns in Bed	2	0.8
Not Sleeping at all	1	0.4
Sleeping with Mother	1	0.4
Snores	1	0.4
Wetting or Bad Dreams	1	0.4
Occasional Nightmares	1	0.4
Not Enough Sleep	1	0.4
Wets Bed	1	0.4
Two or More Sleep Disturbances	73	30.5
No Sleep Disturbance Reported	89	37.2

4.3.2.1 Average Sleep per Night

Children considered by their parents to have a sleep problem slept less on average ($M = 8.2$ hours, $SD = 1.5$) than children whose parents did not perceive their child to have a sleep problem ($M = 9.4$ hours, $SD = 1.3$). A 2-tailed independent samples t -test showed a significant difference for parental perception of a sleep problem and the average amount of sleep per night, $t(235) = -5.87$, $p < .001$.

4.3.2.2 Medical Conditions, Medication use, and Sleep

Children with a medical condition were more inclined to disrupt their parent's sleep (61.4%) than those children who did not have a medical condition (33.1%), $\chi^2(1, N = 237) = 18.74$, $p < .001$, $V = .28$. Furthermore, parent perception

of a child sleep problem was higher for children who had a medical condition (35.9%) compared to children without a medical condition (20.4%), $\chi^2(1, N = 240) = 7.14, p = .008, V = .17$.

Children with epilepsy had a significantly higher prevalence rate of sleep problems, as perceived by parents (38.8%), compared to children without epilepsy (24.1%), $\chi^2(1, N = 240) = 4.26, p = .039, V = .13$. In relation to specific medical conditions, parents who had a child with an ID and epilepsy had a significantly higher rate of sleep disruption due to their child's sleep (62.5%), compared to parents whose child did not have epilepsy (40.7%), $\chi^2(1, N = 237) = 7.32, p = .007, V = .18$.

The presence of a sleep problem, as perceived by parents, was significantly higher for children currently taking medication (36.2%), as opposed to children not taking medication (18.8%), $\chi^2(1, N = 238) = 9.12, p = .003, V = .20$. Parents who had a child with an ID taking medication reported significantly higher rates of having their own sleep disturbed (58.7%) compared to parents whose child was not taking medication (33.6%), $\chi^2(1, N = 235) = 14.74, p < .001, V = .25$.

In relation to specific medication use, children currently taking medication for behaviour management had significantly higher prevalence rates of problematic sleep behaviour (85.7%), compared to those children not taking this type of medication (60.6%), $\chi^2(1, N = 239) = 5.19, p = .023, V = .15$.

4.3.2.3 Sleep Problems and age

An association was found between the child's age and parental ratings of sleep disturbance. Parents who indicated that their sleep was disrupted as a result of their child's sleep had children who were significantly younger ($M = 9.8$ years, $SD =$

4 years), than the children of parents whose sleep was not disturbed, ($M = 11.1$ years, $SD = 3.9$ years), $t(229) = -2.5$, $p = .013$. However, there was no significant difference between age and parent perceptions of sleep problems. There was a tendency for younger children to be classified as having a sleep problem as perceived by parents. Five (41.7%) children aged less than five years had a sleep problem, while 21 (30%) of the children aged five to eight years had a sleep problem. This is compared with 19 (27.9%) children aged from eight to twelve who had a sleep problem, and 20 (23.8%) children aged over twelve years who were regarded by their parent as having a sleep problem.

4.3.2.4 Types of Sleep Problems and Parent Perception

Of the 65 parents who perceived their child to have a sleep problem, 49 (75.4%) rated their child as having a night waking problem, while 37 (56.9%) reported their child woke early in the morning, and 31 (47.7%) noted problems with their child settling to sleep at night. A further 6 (9.2%) stated other types of sleep disturbance, and 45 (69.2%) parents listed their child as having two or more of the above sleep disturbances.

Parental perception of a sleep problem was significantly more frequent when the child displayed night waking (79%) as opposed to when the child displayed another type of problematic sleep behaviour (21%), $\chi^2(1, N = 149) = 22.2$, $p < .001$, $V = .39$. Parental perception of a sleep problem was also significantly more frequent when the child exhibited two or more problematic sleep behaviours (72.6%) compared to when the child had one problematic sleep behaviour (27.4%), $\chi^2(1, N = 149) = 23.6$, $p < .001$, $V = .40$.

4.3.2.5 Sleep Problems Across Disability Types

The sleep questionnaire was also considered across the five disability groups present in the sample. As rated by parents, children with a pervasive developmental disorder (PDD) had an average sleep time of 9.1 hours per night, ($SD = 1.4$, $N = 108$), compared to children with an ID of unknown aetiology (ID) who slept an average of 8.9 hours per night, ($SD = 1.5$, $N = 68$), and children with Down's syndrome who slept 9.2 hours on average per night, ($SD = 1.2$, $N = 29$). Children who had a other diagnosis associated with an ID (Oth ID) slept 9.2 hours per night on average, ($SD = 1.6$, $N = 22$), and children with cerebral palsy (CP) slept an average of 9 hours per night, ($SD = 1.5$, $N = 13$). The frequencies and percentages of demographic data and sleep data across type of disability are reported in Table 4.4. A significant difference was found between the presence of a medical condition across the disability groups, $\chi^2(4, N = 243) = 16.9$, $p = .002$, $V = .26$, as well as medication use among children in the respective disability groups, $\chi^2(4, N = 241) = 12.4$, $p = .015$, $V = .23$. No significant differences were found between the disability diagnoses in relation to any of the sleep variables. Prevalence rates of sleep problems as perceived by parents ranged between 25% and 38.5% across the five disability groups.

4.3.2.6 Parents who Rated Their Child as Displaying Problematic Sleep

Behaviour but did not Perceive Their Child to Have a Sleep Problem

The large discrepancy between a parent-reported sleep difficulty (night settling, night waking, early morning waking, or other difficulties, 62.8%, $N = 239$) and whether parents believed that their child had a sleep problem (27.1%, $N = 240$) was explored further. Where parents considered their child to have a sleep problem,

Table 4.4. Frequencies and Percentages of Medical Conditions, Medication use, and Sleep Ratings Across Disability Groups

Variable	Disability Type									
	PDD		ID		DS		Oth ID		CP	
	(n = 110)		(n = 69)		(n = 29)		(n = 22)		(n = 13)	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Medical Condition	36	(32.7)	40	(58.0)	8	(27.6)	12	(54.5)	8	(61.5)
Epilepsy	15	(13.6)	25	(36.2)	0	(0.0)	5	(22.7)	4	(30.8)
Asthma	9	(8.2)	7	(10.1)	2	(6.9)	5	(22.7)	2	(15.4)
Medication Use	42	(38.5)	36	(52.2)	7	(24.1)	13	(59.1)	8	(66.7)
Sleep Difficulties	70	(65.4)	44	(64.7)	13	(44.8)	13	(59.1)	10	(76.9)
Early Waking	33	(30.8)	16	(23.5)	5	(17.2)	4	(18.2)	4	(30.8)
Night Waking	39	(36.4)	24	(35.3)	6	(20.7)	9	(40.9)	6	(46.2)
Settling	35	(32.7)	26	(38.2)	7	(24.1)	10	(45.5)	6	(46.2)
Other	5	(4.7)	4	(5.9)	2	(6.9)	0	(0.0)	0	(0.0)
Two or More	34	(31.8)	19	(27.9)	6	(20.7)	9	(40.9)	5	(38.5)
Severity Rating										
Mild	45	(65.2)	23	(53.5)	9	(69.2)	9	(69.2)	6	(60.0)
Moderate	22	(31.9)	18	(41.9)	2	(15.4)	3	(23.1)	3	(30.0)
Severe	2	(2.9)	2	(4.7)	2	(15.4)	1	(7.7)	1	(10.0)
Parent Sleep Disrupted	48	(43.6)	27	(42.2)	10	(34.5)	14	(63.6)	8	(66.7)
Parent Perceived Child to have a Sleep Problem	29	(26.6)	17	(25.0)	7	(25.0)	7	(31.8)	5	(38.5)

PDD = Pervasive Developmental Disorder; ID = Intellectual Disability of unknown aetiology; DS = Down Syndrome; Other ID = Diagnosis associated with the presence of ID; CP = Cerebral Palsy. ^a Due to low numbers, three children who presented with a PDD and CP were added to the PDD group as this is considered to be the child's primary diagnosis.

these children slept significantly less on average ($M = 8.2$ hours, $SD = 1.5$ hours), than those children who exhibited problematic sleep but the parents did not perceive the child to have a sleep problem ($M = 9.3$ hours, $SD = 1.4$ hours), $t(144) = -4.47, p < .001$.

Seventy-four (80.4%) of the parents in the mild severity group, and 12 (25%) parents in the moderate severity rating group did not perceive their child to have a sleep problem. Also, 28 (38.4%) parents indicated that their child exhibited two or more problematic sleep behaviours, however, they did not perceive their child to have a sleep problem.

For the children with only one reported sleep difficulty, there was a significant difference in the severity rating between parents who rated their child as having a sleep problem and those parents who did not ($M = 1.8, SD = 0.7$ and $M = 1.1, SD = 0.3$ respectively), $U = 213.00, z(N = 74) = -4.76, p < .001$. Similarly, children with two or more sleep difficulties whose parents rated their child as having a sleep problem gave a significantly higher severity rating than those whose parents did not ($M = 1.8, SD = 0.6$ and $M = 1.2, SD = 0.4$ respectively), $U = 288.00, z(N = 73) = -4.34, p < .001$. Sleep difficulties associated with parent belief that there is a sleep problem are reported in Table 4.5.

4.3.2.7 Predicting Parental Perception of a Sleep Problem

A direct binary logistic regression analysis was performed with parent perception of a sleep problem as the dependant variable. The child's age, gender, diagnosis, presence of a medical condition, use of medication, average sleep length per night, the presence of night settling, early waking, night waking, and two or more sleep difficulties, severity ratings, and parental sleep disruption as a result of the

child's sleep were the predictors. Data from 136 participants were available for analysis, 57 were parents who considered their child to have a sleep problem, and 79 did not perceive their child to have a sleep problem. Overall, the regression model was significant, $\chi^2 (16 = 94.1)$, $p < .001$, indicating that the predictors as a set reliably distinguished between parents who perceived their child to have a sleep problem and those who did not. The variance in sleep problem perception status was moderate, with Nagelkerke's R square = .67. Prediction success was also moderate, with 86.1% of parents in the no sleep problem group and 77.2% of parents in the sleep problem group correctly predicted, for an overall success rate of 82.4%.

Table 4.5. Types of Sleep Difficulties and Frequencies (%) for Parental Perception of a Child Sleep Problem and Parental Sleep Disruption Due to the Child's Sleep

Type of Sleep Difficulty	<i>n</i>	Parent Thinks Child has a Sleep Problem (%)		Parent Sleep Disrupted Due to Child's Sleep (%)	
		Yes	No	Yes	No
Settling ^a	61	50.8	49.2	62.3	37.7
Night Waking ^b	82	59.8	40.2	86.6	13.4
Early Waking ^b	82	45.1	54.9	78.0	22.0
Other	11	54.5	45.5	72.7	27.3
None Reported ^c	87	3.4	96.6	5.7	94.3

aOne parent did not complete this section of the survey.

bTwo parents did not complete this section of the survey.

cThree parents did not complete this section of the survey.

According to the Wald criterion, parent sleep disruption due to the child's sleep ($z = 10.71$, $p = .001$), severity ratings ($z = 11.93$, $p = .003$), the child's age ($z = 5.96$, $p = .015$), the number of hours the child slept per night ($z = 5.13$, $p = .024$), and

the gender of the child ($z = 3.93, p = .047$) contributed significant amounts of unique predictive variability. Thus, parents whose sleep was disrupted due to the child's sleep had a higher probability of perceiving their child to have a sleep problem. Furthermore, parents who rated their child's sleep problem as mild, as opposed to moderate or severe, had a lower probability of perceiving their child to have a sleep problem. Also, parents who had a younger child, a child with a short sleep length, and a child who was female, had a higher probability of perceiving their child to have a sleep problem.

4.3.3 Treatment

For those parents who reported their child to have a sleep problem, the duration of the sleep problem ranged from 1 month to 17.5 years ($M = 7.1$ years, $SD = 4.5$ years, $N = 55$). Two (3.6%) of the children had presented with the sleep problem for less than 1 year, while 8 (14.5%) had exhibited the sleep problem for between 1 to 3 years, and for 44 (80%) of the children the sleep problem had lasted for more than 3 years. Two children had been diagnosed with sleep apnoea, while none of the other children had a formal diagnosis of any sleep disorder.

Two of the 65 parents who said that their child had a sleep problem did not complete the treatment section of the questionnaire. Forty-eight (76.2%) parents had sought treatment for their child's sleep problem. Of these 48 families, medication was tried by 31 (64.6%), behavioural treatment was used by 24 (50%), herbal treatment was tried by 8 (16.7%), and 5 (10.4%) had used some other form of treatment for their child's sleep problem (Appendix F).

Eighteen families had sought two of these treatments, and seven families had sought three of these treatments. The herbal and other treatment groups were

combined and the efficacy of medication, behavioural, and other treatments compared. Three of the 48 parents were not included due to incomplete data. The average rating for other treatment was 4.6 ($SD = 3.3$), for medication the average was 3.7 ($SD = 3.2$), and for behavioural treatment the average was 3.2 ($SD = 3.5$) (ratings have been converted to a 10-cm scale for comparison with Robinson & Richdale, 2004). A Kruskal Wallis one-way analysis of variance revealed that there was no significant difference between ratings of intervention success for the different sleep treatment methods, $\chi^2(2, N = 60) = 1.80, p = .41$.

4.4 Discussion

The first hypothesis regarding prevalence rates for sleep problems was not supported. The obtained prevalence rate of parent reported child sleep problems of 27.1% was lower than expected. Hypotheses two, that approximately 20% of parents would not perceive their child to have a sleep problem even though it existed, was partially supported. Of 150 parents who rated their child as displaying settling, night waking, and/or early waking difficulties, 85 (56.7%) parents did not consider their child to have a sleep problem.

Hypothesis three, that about half the parents would seek help for their child's sleep problem was partially supported. Over three quarters of parents in this study sought help for their child's current sleep problem. The final hypothesis, that behavioural treatments for sleep problems would be rated more favourably than medication and other treatments, was not supported. There was no significant difference between the treatment ratings.

4.4.1 Prevalence Rates and Parental Perceptions of Sleep Problems

Based on previous literature, the sleep problem prevalence rate was lower than expected, however, it was comparable to rates obtained in three previous studies (Clements et al., 1986; Didden, et al., 2002; Robinson & Richdale, 2004). Overall, 62% of parents rated their child as displaying problematic night settling, night waking, early waking, or other disturbing sleep behaviours, however, only 27% of parents actually considered their child to have a sleep problem. Further analysis of this intriguing finding revealed that children regarded as having a sleep problem obtained significantly less sleep, were more likely to exhibit night waking, and displayed two or more sleep difficulties, as opposed to the children who displayed disturbed sleep but were not regarded as having a sleep problem. This suggests that the children perceived to have a sleep problem displayed more severe disturbance.

However, a number of parents rated their child's disturbance as moderate, or indicated the presence of two or more sleep disturbances, but they did not perceive their child to have a sleep problem. Furthermore, almost half of the parents who rated their own sleep as being disrupted as a result of their child's sleep, did not consider their child to have a sleep problem. These figures indicate that some parents fail to identify their child's sleep problem despite the presence of significant sleep disturbance. This phenomenon has been reported previously in the literature (Bartlett et al., 1985; Wiggs, & Stores, 1996a; Didden et al., 2002).

For those parents who perceived their child to have a sleep problem, the average duration of the sleep problem was seven years. This result is the same as that reported by Wiggs and Stores (1996b) and supports previous research outlining the persistent nature of sleep problems in children with an ID (Bramble, 1996; Quine, 1991; Richdale et al., 2000). However, despite the chronic nature of these sleep

problems, parents in this study generally rated problem severity to be moderate, or even mild, rather than severe.

Thus, there is considerable variability between parents regarding perception of a sleep problem in children with an ID. This variability may be due to a combination of factors existing within the child or the parent, or both. In this study a logistic regression analysis revealed that parent sleep disruption, sleep problem severity ratings (higher), age of the child (younger), parent estimations of hours slept per night (shorter hours), and gender (female) of the child were the most important factors determining parental perception of a sleep problem. However, as reported earlier, there were a number of parents whose sleep was disturbed, or who rated their child's sleep difficulty to be moderate, who still did not consider their child to have a sleep problem.

Therefore, sleep problem perception is variable: It may be related to cultural differences, child-rearing practices, parental beliefs regarding the cause of the sleep problem, or parent beliefs that the sleep problem is part of the child's disability and cannot can be treated (Bramble, 1996; Stores, 2001). Other factors such as problematic daytime behaviour, parent stress, and perceived control over the child's sleep behaviour may also be related to parent perception of sleep problems in children with an ID (Quine, 1991; Wiggs & Stores, 1998b). To date, only one study has been conducted to investigate possible characteristics to explain why some parents underrate their child's sleep problem (Wiggs & Stores, 1998b), and further investigation within this area is necessary.

4.4.2 Treatment

The proportion of parents who had sought treatment for their child's sleep problem was much higher in this study than what has been reported previously (Bartlett et al., 1985; Didden et al., 2002; Wiggs & Stores, 1996b). Over 75% of parents had tried at least one type of intervention to ameliorate their child's sleep problem. This higher rate suggests that some parents may be more amenable to seeking treatment for their child's sleep problem than others. However, the higher rate obtained in this study may be due to the fact that some parents had apparently attempted their own treatment as opposed to seeking professional help for the problem. While many parents did not provide sufficient information to determine if the treatment tried was the result of professional advice or not, some parents' explanations regarding treatment indicated that a self-help approach had been taken. In the past parents have indicated that they have not sought professional treatment because they thought they could rectify the problem themselves (Study 1, Robinson & Richdale, 2004). Conversely, some parents believe the problem is part of the child's disability and therefore, cannot be treated (Bramble, 1996; Robinson & Richdale, 2004). These parents may not be prepared to seek professional help, but may attempt to manage/treat the sleep problem themselves.

The average parent ratings for treatment success were poor for all treatment methods, and a significant difference between treatment methods was not found. This result was unexpected given previous studies that have reported higher parental ratings of success with the use of behavioural intervention (Bramble, 1996; Wiggs & Stores, 1996b). However, the finding in this study corresponds to that of a recent study by Didden et al. (2002) where sleep problem treatment was rated as effective in only 34.6% of cases. For some parents who tried behavioural treatment poor

ratings may be explained by either poor treatment advice, or a self-help attempt by the parent. Wiggs and Stores (1996b) reported that some parents who received behavioural advice for their child's sleep problem were given incorrect or inappropriate advice.

4.4.3 Medical Conditions and Medication Use

In this study, the presence of epilepsy and current use of an antiepileptic were associated with sleep problems. Children with epilepsy, and children who were currently taking antiepileptic medication were more likely to wake at night, display two or more problematic sleep behaviours, disrupt their parent's sleep, and were more likely to be perceived by parents as having a sleep problem. This is consistent with previous studies that have reported an association between epilepsy and sleep problems (Didden et al., 2002; Quine, 1991).

The presence of asthma was not associated with problematic sleep. This was most likely because the information in this study was obtained subjectively through parent report. A previous study that used parent report to examine the relationship between sleep problem prevalence and asthma also did not find a significant relationship (Tirosh et al., 1993). In contrast, previous studies that have used both subjective and objective measurements that included the use of wrist actigraphs, peak-flow meters, and polysomnography have found an association between asthma and a higher rate of sleep problems in children (Sadeh et al., 1998; Stores et al., 1998). The main sleep abnormality associated with asthma is frequent wakings that interrupt sleep continuity and cause the child to experience difficulty waking in the morning, decreased alertness, and increased tiredness during the day. These wakings can be brief and can often go unnoticed without careful monitoring (Stores et al.,

1998). Therefore, physiological sleep recordings would provide a more informative account of the association between sleep problems and asthma in children with an ID.

4.4.4 Limitations of Study

A limitation of this study was the lower than expected response rate compared to recent studies in this area (Didden et al., 2002; Wiggs & Stores, 1996b), although a 12% response rate has been reported in the literature (Honomichl et al., 2002). The lower response rate may be due to the method of recruitment, some of the schools being placed in regions of lower socio-economic status with a high number of families from non-English speaking backgrounds, or the high levels of stress endured by parents who have a child with an ID, especially if the child has a chronic sleep problem (Richdale et al., 2000). These factors may have prevented some parents from completing the questionnaire.

Despite approaching 24 special schools, special developmental schools, and one early intervention centre, and using a short questionnaire in an attempt to gain a higher response rate, the reply rate for this study was comparable to that obtained by the author in a previous, similar study (Robinson & Richdale, 2004). Also, the questionnaire used only obtained brief information regarding the types of treatment that parents sought for their child's sleep problem. This made it difficult to discern whether parents had obtained advice from professionals or if they had attempted to treat the sleep problem of their own accord. This may have impacted the ratings obtained for the different treatment methods.

Another limitation of the study was the heterogeneity of the sample: This limits interpretation regarding specific disorders, and places restrictions on the

conclusions being made. However, these limitations are common within this literature (Didden & Sigafos, 2001) and a heterogeneous group is often required due to low participation rates and the low frequency of many developmental disorders.

A further limitation of the study was the lack of information provided in the treatment section of the questionnaire. This made it difficult to discern between the different types of treatment, especially behavioural and other interventions. Thus, some interventions belonging to the behavioural treatment group may have been more suited to another treatment category. This limitation may explain why behavioural treatment did not get rated highly, and should be taken into consideration when interpreting the results comparing success ratings across treatment types.

4.4.5 Summary and Conclusions

The results of this study indicate that sleep problems in children with an ID are prevalent and often chronic. Furthermore, there appear to be many parents who underrate their child's sleep disturbances and thus do not perceive that a sleep problem is present. Given the persistent nature and debilitating effects that sleep problems can have for the entire family, future research aimed towards identifying the factors that lead parents to undervalue a chronic child sleep disturbance is essential. Once identified, prospective educational resources and treatment protocols may be able to address this issue and encourage these parents to attempt to ameliorate the sleep problem.

Some parents do not seek treatment for their child's sleep problem, while those who do largely report unsuccessful results. These findings are contrary to

research studies that advocate behavioural intervention as a highly successful and acceptable form of intervention for sleep problems in children with an ID. Clearly, the message is not being conveyed to parents that sleep problems in children with an ID are treatable. Therefore, health professionals require training in relation to the assessment and treatment of sleep problems for children who have an ID. Increased professional awareness of the relevant treatment issues, and barriers to treatment, would help parents choose and implement suitable intervention strategies that are known to resolve specific sleep problems in this population.

CHAPTER 5. STUDY 2: FACTORS AFFECTING PARENTAL PERCEPTION OF SLEEP PROBLEMS IN CHILDREN WITH AN ID

5.1 Study Rationale, Aims, and Hypotheses

Previous research has found an association between sleep problems in children with an ID and various child and parent factors. Specifically, difficult child daytime behaviour, communication problems, and parent stress have been linked to the presence of sleep problems in children with an ID (Didden et al., 2002; Piazza et al., 1996; Quine, 1991; Richdale et al., 2000; Wiggs & Stores 1996a). Stable parent personality traits have also been associated with the presence of sleep problems in TD children (Gelman et al., 1998). Furthermore, studies on TD children and children with an ID have reported that some parents do not recognise or perceive that their child has a sleep problem even though one exists (Atkinson et al., 1995; Bartlett et al., 1985; Scott & Richards, 1998; Wiggs & Stores, 1996a).

Wiggs and Stores (1998b) examined child and parent factors that affected whether or not mothers recognised that their child had a sleep problem. Mothers who failed to recognise their child's sleep problem were different from mothers who did perceive that their child had a sleep problem. The mothers who did not perceive a sleep problem reported significantly less difficult child daytime behaviour, and significantly less stress. A higher perceived control over the child's sleep and a lower external locus of control were also thought to act as stress moderators in these mothers.

Thus, the aim of Study 2 was to determine the influence of child and parent factors on parental perception or recognition of sleep problems in children with an ID. Based on previous literature the study had six hypotheses. Compared to parents

who did recognise/perceive their child's sleep problem, it was hypothesised that parents who did not recognise/perceive that their child had a sleep problem would report the following:

1. Lower problematic daytime and adaptive child behaviour.
2. Less parental stress.
3. Higher levels of perceived control over the child's sleep and daytime behaviour.
4. Higher levels of parental competence.
5. A higher internal locus of control.
6. A lower level of neuroticism, and a higher level of extraversion.

5.2 Method

5.2.1 Participants

Participants in Study 2 were primarily parents/carers of children with an ID who had been involved in Study 1, and who had expressed an interest in participating in Study 2. One parent in Study 2 had not participated in Study 1. In total, 106 (43.6%) parents/primary carers from Study 1 expressed an interest in Study 2 and were contacted via telephone from October 2001 to March 2002 about participating in Study 2. Ninety-six (90.6%) parents/carers agreed to participate in Study 2, while seven (6.6%) were not contactable, two (1.9%) were considered to be inappropriate for the study because they had limited English (compared to Study 1 the length and complexity of the questionnaires in Study 2 was more onerous), and one parent/carer (0.9%) refused to participate. Of the 96 questionnaire packages that were distributed to parents/carers, 76 (79.2%) were completed and returned to the researcher.

5.2.2 Materials

5.2.2.1 Demographic Details

The demographic details sheet (Appendix G) consisted of 15 questions including completion date of the questionnaires, the child's date of birth, the participant's relationship to the child, their ethnicity, education level, and current occupation, the number of children in the family, and whether the child attended a special school (for children with an IQ between the range of 50-70) or special developmental school (for children with an IQ less than 50). Participants were also asked to provide their child's specific diagnosis (eg Autism, Down's Syndrome), and state whether they thought their child had a sleep problem and provide a brief explanation for their answer.

5.2.2.2 Sleep Measure

The Behavioural Evaluation of Disorders of Sleep (BEDS) (Schreck, 1997/1998; Schreck, Mulick, & Rojahn, 2003) is a parent report sleep questionnaire that was developed from distinct ICSD (American Sleep Disorders Association, 1991) diagnostic criteria for parasomnias and dyssomnias that occur during childhood. It consists of 107 descriptive statements constructed from the ICSD criteria for individual sleep disorders with items answered on a five-point scale where 0=Never, 1=Rarely, 2=Sometimes, 3=Frequently and 4=Always. A further four questions relating to hours slept per night, hours slept in the last 24 hours, hours spent napping, and parental perception of a sleep problem are also included. Higher scores are indicative of greater sleep disturbance as rated by parents.

Exploratory factor analysis conducted on a sample of 307 TD children aged 5 to 12 years provided five factors. Factor 1 Expressive Sleep Disturbance (ESD)

relates to observable sleep disturbances such as sleep walking and waking and screaming; Factor 2 Sensitivity to the Environment (SE) examines sleep disruption due to various environmental stimuli; Factor 3 Disoriented Awakening (DA) concerns symptoms of sluggishness or disorientation upon waking; Factor 4 Sleep Facilitators (SF) considers whether medication or a pacifier is required to initiate sleep onset; and Factor 5 Apnoea relates to sleep-breathing difficulties and bruxism (Schreck et al., 2003). Overall for the five factors the internal consistency coefficient was 0.77. The expressive sleep disturbance factor had an internal consistency coefficient of 0.80. The sensitivity to the environment factor was 0.60, for disoriented awakening it was 0.78, for sleep facilitators it was 0.69, and for the apnoea/bruxism factor the internal consistency coefficient was 0.25.

A confirmatory factor analysis for the BEDS was conducted on 1054 TD children aged from 5 to 12 years to test the goodness of fit of the five-factor model. The sleep facilitators factor did not significantly fit the model, however, the remaining four factors of the BEDS significantly fitted the model. The internal consistency coefficient was 0.82 for these four factors. The expressive sleep disturbance factor yielded a coefficient of 0.85. The sensitivity to the environment factor was 0.65, for disoriented awakening it was 0.79, and for the apnoea/bruxism factor the internal consistency coefficient was 0.60. Each factor reliably distinguished between children with and without sleep problems. Using a catalogue of scale statements associated with the diagnostic criteria from the ICSD it is also possible to calculate a score for dyssomnias as well as parasomnias (Schreck, 1997/1998).

5.2.2.3 Child Behaviour Measure

The Developmental Behaviour Checklist (first edition) – Primary Carer Version (DBC) (Einfeld & Tonge, 1994) was used to assess the emotional and behavioural disturbance of children and adolescents with an ID. The DBC takes about 15 minutes to complete, and contains 96 items that are rated either as *0=Not True*, *1=Somewhat or Sometimes True*, and *2=Very True or Often True*. Higher scores denote more severe emotional and behavioural disturbance.

In 2002 a second edition of the DBC was released. The questions in the new version were identical, however, the subscale factors were different (Einfeld & Tonge, 2002). Therefore, the results in this Study were analysed using the second edition of the DBC. The DBC contains three sleep related items: Item 30-*Has nightmares, night terrors or walks in sleep*; item 67-*Sleeps too little. Disrupted sleep*; and item 69-*Sleeps too much*. While parents/carers answered these items, they were removed from any analyses.

Scoring occurs at three levels. The Total Behaviour Problem Score (TBPS) is calculated by summing responses to all 96 items. Five behavioural subscale scores are provided: Disruptive/antisocial, self-absorbed, communication disturbance, anxiety, and social relating. Subscale scores are also provided for five specific psychiatric syndromes: Autism, depression, psychosis, hyperactivity, and anxious behaviour. Finally, individual item scores can be examined for each of the 96 items. A clinical cut-off is also provided for the total behaviour problem score, however, this includes the three sleep related items.

When completed two weeks apart, the DBC has a Test-Retest reliability of 0.83, and an Intra-class correlation of 0.80 has also been reported. Factorial validity

was assessed via principal component analysis. The subscales were derived by including factor items with loadings above 0.30 included.

Concurrent validity revealed significant Pearson correlations when the total behaviour problem score of the DBC was compared to scores on other instruments used to assess psychopathology in children with an ID.

5.2.2.4 Measure of Adaptive Behaviour

The Adaptive Behaviour Assessment System (ABAS) – parent form (Harrison & Oakland, 2000) is a comprehensive assessment of adaptive skills of people aged from 5 to 21 years. Norm referenced scores are provided for 10 adaptive skill areas, communication, community use, functional academics, home living, health and safety, leisure, self-care, self-direction, social, and work. The work section was not applicable in this study as all participants were at school, hence parents were directed not to complete this section of the form. Therefore, parents completed 211 out of the 232 items for this questionnaire. Items are answered on a four-point scale where *0=Is not able*, *1=Never or Almost Never When Needed*, *2=Sometimes When Needed*, and *3=Always or Almost Always When Needed*. Higher scores indicate greater competence in the relevant adaptive skill. Scaled scores for the adaptive skill areas can be calculated, as can a general adaptive composite that in turn yields a percentile rank.

Average reliability coefficients of the adaptive skill areas as reported for 199 people with an ID ranged from 0.91 to 0.97. For the parent form, test-retest intervals of between 1 to 2 weeks yielded reliability coefficients ranging from 0.79 to 0.94. Furthermore, inter-rater reliability coefficients of the parent form based on 81 children, adolescents, and young adults aged 5-21 years ranged from 0.61 to 0.81.

Confirmatory factor analysis conducted on the standardisation samples confirmed that the ABAS assesses a strong and unified single factor of adaptive skill. Furthermore, clinical validity studies with persons with an ID compared to matched control groups have provided consistent results. For the adaptive skill areas the ID sample reported average scale scores that were very low, and much lower than the control group.

5.2.2.5 Personality Measure

A short form of the revised version of the Eysenck Personality Questionnaire (EPQ-R) was used to consider the extraversion-introversion and neuroticism-stability dimensions of personality (Eysenck & Eysenck, 1991). The EPQ-R is based on literature by Eysenck (1967) that recognised three distinct dimensions of personality, extraversion-introversion, neuroticism, and psychoticism. The short scale consists of 48 items to which respondents answer either yes or no. Factors are obtained on four scales: Psychoticism, extraversion, neuroticism, and lie. For males, reliability on the psychoticism scale is 0.62, for extraversion it is 0.88, while for neuroticism reliability is 0.84, and for the lie scale it is 0.77. For females, reliability on the psychoticism scale is 0.61, for extraversion it is 0.84, while for neuroticism reliability is 0.80, and for the lie scale it is 0.73.

5.2.2.6 Parent Competence Measure

The Parenting Sense of Competence (PSOC) scale is a 16-item questionnaire that delineates two dimensions of parenting self-esteem, referred to as efficacy and satisfaction. The efficacy dimension examines perceived parent competency, problem solving capability, and familiarity with parenting. The satisfaction

dimension refers to frustration, anxiety, and motivation within the parenting role (Johnston & Mash, 1989). Items are answered on a six-point scale where *1=Strongly Agree*, *2=Agree*, *3=Mildly Agree*, *4=Mildly Disagree*, *5=Disagree*, and *6=Strongly Disagree*. Higher scores indicate greater satisfaction and efficacy in the parenting role. In a sample of 4 to 9 year-old boys and girls the PSOC obtained alpha coefficients of 0.75 and 0.76 for the satisfaction and efficacy scales respectively. PSOC scores were not found to vary as a function of child age or gender (Johnston & Mash, 1989).

5.2.2.7 Measure of Parent Stress

The Parenting Hassles Scale (PHS) short form (Gavidia-Payne & Stoneman, 1997) was used to measure everyday stresses experienced by parents of children with an ID. It contains 51 items that are answered on a five-point Likert scale where *1=No Hassle*, *2=Minor Hassle*, *3=Moderate Hassle*, *4=Severe Hassle*, and *5=Major Hassle*. Higher scores indicate greater feelings of stress. The PHS contains two sleep related items: Item 20-*I have problems getting my child to bed or sleep*; and item 21-*My child has sleep problems, wakes up often*. While parents/carers answered these items, they were removed from the main analysis.

The PHS short form contains three subscales: Child behaviour/needs, parental needs/characteristics, and education and child development. Their alpha coefficients are 0.88, 0.87, and 0.87 respectively.

5.2.2.8 Measure of Locus of Control

Levenson's (1973) Locus of Control Scale (LOC) is a 24-item questionnaire that was used to examine participants' generalised expectancy to perceive

reinforcement either as contingent upon their own behaviours (internal control), or as the result of forces beyond their control (external) or due to chance, fate, or powerful others (Rotter, 1966). Two types of external orientation are the belief in a random, unordered nature, and the belief in order and predictability in conjunction with the expectancy that powerful others are in control. These three subscales each consist of eight items that are answered on a six-point Likert scale where 1=*Disagree Strongly*, 2=*Disagree Somewhat*, 3=*Disagree Slightly*, 4=*Agree Slightly*, 5=*Agree Somewhat*, and 6=*Agree Strongly*. Higher scores indicate high expectations of control for that subscale, while low scores indicate a propensity not to believe in the locus of control for that subscale.

Kuder-Richardson reliabilities based on an adult sample yielded 0.51 for the Internality scale, 0.72 for the powerful others scale, and 0.73 for the chance scale. Spearman-Brown split-half reliabilities are 0.62 for the internality scale, 0.66 for the powerful others scale, and 0.64 for the chance scale respectively. A 7-week interval reported test-retest reliabilities of 0.66 for the internality scale, 0.62 for the powerful others scale, and 0.73 for the chance scale. The validity of the scales has been demonstrated through convergent and discriminant methods revealing significant low-order correlations with other measures of the general locus of control construct, in conjunction with a theoretically-based pattern of positive and negative correlations with other variables (Levenson, 1981).

5.2.2.9 Perceived Control over the Child's Sleep and Daytime Behaviour

This study used the perceived control measure used by Wiggs and Stores (1998b). It consisted of two, 10-centimetre visual analogue scales to examine participants' perceived control over any difficult sleep behaviour pattern displayed

by their child, and their perceived control over any difficult daytime behaviour displayed by their child. Extreme statements of *0cm = Not at all able to control it*, and *10cm = Totally able to control it* anchored each end of the scale. High scores indicated greater perceived control.

5.2.3 Procedure

The RMIT University Human Research Ethics Committee approved Study 2 (Appendix C). Participants who were involved in Study 1 and had indicated an interest in participating in Study 2 were contacted by the researcher who outlined the nature of the study and gained consent to send out the questionnaires. Questionnaire packages were mailed to participants and consisted of the measures described in conjunction with a plain language statement that outlined the research (Appendix H), and a consent form (Appendix I) to be completed by the participant. All participants were then contacted again, via telephone, within two weeks of the packages being sent out to clarify any questions regarding the materials and the nature of the study. Further contact was made after another three weeks for those participants who had not returned the materials. Completed questionnaires were returned to the researcher via a reply paid envelope.

5.2.4 Data Analysis

Children in the no sleep problem group were classified as having a sleep problem that was not perceived or not recognised by the child's parent/carer if the child scored above one standard deviation over the mean scores for children in the no sleep problem group on any BEDS factor that had revealed significant differences

between children in the sleep problem group and those in the no sleep problem group (Total score, Dyssomnias, Parasomnias, Expressive Sleep Disturbance, and the Apnoea factors). Scoring one standard deviation above the mean scores of the children in the no sleep problem group indicated that for at least one sleep factor the child's sleep more closely resembled that of the children in the recognised sleep problem group.

Data were analysed quantitatively using version 10.0 of the Statistical Package for the Social Sciences (SPSS). An independent *t*-test for two sample designs was used to compare the sleep groups on the BEDS factors. For three sample designs a multivariate analysis of variance (MANOVA) was conducted on the adaptive behaviour and daytime behaviour factor scores. While a series of single-factor between-subjects analysis of variance (ANOVA) with an adjusted alpha level were performed to test for a difference between sleep groups on measures of parent stress, personality, locus of control, and parenting competence. Due to the number of ANOVAS conducted the alpha level was adjusted from 0.05 to 0.01 to prevent the occurrence of type 1 errors. Where significant effects were obtained, subsequent post-hoc tests were conducted using the Tukey-Kramer procedure. The Levene test statistic will only be reported and referred to where the assumption of homogeneity of variance is violated. A multinomial regression was performed to determine the variables that best predict sleep group membership. Differences between the three sleep groups were examined in relation to disability type using a series of Kruskal-Wallis tests with multiple comparisons made using Mann-Whitney tests.

5.3 Results

Exploratory data analysis was conducted to screen for normality, missing data, and outliers. No cases or data points were omitted due to missing data or outliers. Where possible, an imputation method was employed to estimate the small amount of missing data on dependent measures that occurred for some participants. Mean substitution was used to represent missing data. This method is a common way to estimate missing data and involves deriving the mean value obtained from all available data in the sample (Tabachnick & Fidell, 1996). Tests of normality and inspection of normality plots indicated that data for the dependent measures were approximately normally distributed, thus no data transformation procedures were conducted.

5.3.1 Child Demographics

The children in Study 2 were aged from 3.4 and 18.9 years ($M = 10.6$ years, $SD = 4.4$), $N = 76$), 51 (67.1%) of the children were male and 25 (32.9%) were female. Of the 76 children, 30 (39.5%) had a diagnosis of Pervasive Developmental Disorder (PDD), 18 (23.7%) had an ID of unknown aetiology, 14 (18.4%) had Down Syndrome, 4 (5.3%) had cerebral palsy, 1 (1.3%) had both an PDD and Cerebral Palsy, and 9 (11.8%) had an ID as a result of another condition (Table 5.1).

Thirty-six (47.4%) children had a medical condition, 17 (22.4%) had epilepsy, while 7 (9.2%) had asthma, 3 (3.9%) had ADHD, and 13 (17.1%) children had a medical condition of another aetiology (Table 5.2). Medication usage was reported for 32 (42.7%) children, although for 6 children the specific medication was not reported. Twelve (15.8%) children were currently taking anti-convulsant medication for epilepsy, and four (5.3%) were taking an antipsychotic for behaviour

management. Four (5.3%) children were taking a central nervous stimulant, two of which were for the child's ADHD diagnosis and two were for hyperactivity/inattentiveness without a formal diagnosis of ADHD. One (1.3%) child was taking a respiratory inhalant for asthma, and one (1.3%) child was taking an antidepressant for behaviour management. Ten (31.3%) children were reportedly taking multiple medications, and 18 (56.3%) of these children were taking a medication with listed sleep side effects. Appendix J depicts the medications that were taken by children in Study 2, their action, reason for use as listed by the child's parent, and possible sleep side effects.

Table 5.1. The Types and Frequencies of Diagnoses Associated with ID

Type of Medical Condition (<i>n</i> = 9)	Total
Undiagnosed syndrome*	2
Cri du Chat syndrome	1
18q syndrome	1
Chromosome abnormality 8q	1
Sturge-Weber syndrome	1
Metabolic Disorder: Neuro-degenerative/Osteo-degenerative*	1
ID associated with Rubella infection	1
Chromosomal*	1

* Parent did not give further details.

Thirty-nine (51.3%) of the children attended a special school, while 32 (42.1%) went to a special developmental school, 2 (2.6%) went to a combined Special school / special developmental school, and 3 (3.9%) went to an early intervention centre. Sixty-nine (90.8%) of the children were born in Australia, while three (3.9%) were born in Europe, three (3.9%) were born in Asia, and one (1.4%) was born in North America.

Table 5.2. The Types and Frequencies of Other Medical Conditions

Type of Medical Condition (<i>n</i> = 13)	Total
Hearing loss	3
Hearing and vision impaired	2
Multiple Food Allergies	1
Under-active thyroid and heart condition	1
Narrow valve to heart	1
Chronic arthritis	1
Visual impairment and undiagnosed apnoea	1
Retinal dystrophy	1
Dyspraxia	1
Leaking heart valve	1

5.3.2 Parent/Primary Carer Demographics

The primary carers consisted of 68 (89.5%) mothers, 5 (6.6%) fathers, and 3 (3.9%) carers. English was the primary language spoken in the home for 67 (88.2%) families, while 3 (3.9%) families spoke a combination of English and another language, and 6 (7.9%) families primarily spoke a language other than English. The number of children within each family ranged from 1 to 11 ($M = 2.4$, $SD = 1.5$). The majority of parents/carers were born in Australia, had completed secondary school, and were working or performed home duties (Table 5.3).

5.3.3 Parent Perception of a Sleep Problem

Of the 76 participants, 20 (26.3%) considered their child to have a sleep problem. Appendix K displays the individual responses given by participants to explain why they thought their child did/did not have a sleep problem ($N=56$). Seventeen participants indicated that their child displayed problematic sleep at times, however, they did not consider their child to have a sleep problem.

Table 5.3. Parent / Primary Carer Demographics

Parent/Carer Demographic	Participant		Other Parent / Primary Carer	
	<i>n</i>	%	<i>n</i>	%
Place of Birth				
Australia	57	75.0	55	72.5
United Kingdom & Ireland	7	9.2	5	6.5
Europe	4	5.3	6	7.9
Asia	6	7.9	6	7.9
South America	1	1.3	1	1.3
Middle East & Africa	0	0.0	2	2.6
New Zealand	1	1.3	1	1.3
Level of Education				
Did not Complete Secondary	23	30.3	28	36.8
Completed Secondary	17	22.3	15	19.8
Tertiary	36	47.4	31	40.8
Missing/Not Reported	0	0.0	2	2.6
Current Occupation				
Professional/Associate Professional	19	25.0	41	53.9
Tradesperson/Production/Transport/Labour	2	2.6	12	15.9
Service/Sales	16	21.1	2	2.6
Home Duties	34	44.8	4	5.3
Student	2	2.6	0	0.0
Self Employed	2	2.6	2	2.6
Unemployed	0	0.0	4	5.3
Retired	1	1.3	3	3.9
Missing/Not Reported	0	0.0	8	10.5

In the time that elapsed between the completion of Study 1 and the beginning of Study 2, twelve participants changed their answer in relation to sleep problem perception. Eleven of these twelve participants stated in Study 1 that their child had a sleep problem; however, in Study 2 they did not consider this to be the case.

Demographic and sleep related characteristics from Study 1 were further explored for the eleven children who no longer had a parent-perceived sleep problem. Questions relating to sleep severity, sleep problem duration, and treatment were answered by only 9 of the 11 participants in Study 1. The children varied in age (range 3.4 years to 15.3 years), and diagnosis (4 with PDD, 4 with ID, 2 with other

ID, 1 with DS). In Study 1 all eleven participants had considered their own sleep disrupted as a result of their child's sleep, with a variety of sleep problems listed (7 had an early waking problem, 6 had a night waking problem, 5 had night settling problems, 1 had another sleep problem, and 7 displayed two or more sleep problem behaviours). Five of the participants had rated the child's sleep disturbance as moderate in Study 1, and for seven of the participants the child's sleep problem had been present for 3 years or more. Seven participants had sought treatment for their child's sleep problem with effectiveness ratings ranging from 0 to 5.3 out of 10 on the visual analogue scale.

The remaining participant of the twelve who had changed their answer regarding perception of a sleep problem, stated in Study 1 that their child did not have a sleep problem. However, in Study 2 this participant perceived their child as having a sleep problem. Table 5.4 depicts participant responses explaining why this sub-group of 12 participants thought their child did/did not have a sleep problem.

5.3.4 Child Characteristics Across Sleep Groups

For the children in the sleep problem group, the average age was 10.3 years ($SD = 3.7$), compared to an average age of 10.7 years ($SD = 4.6$) for the children in the no sleep problem group. A significant difference was obtained between the two groups for epilepsy, with children in the sleep problem group displaying a higher rate of epilepsy (40%) compared to children in the no sleep problem group (16.1%), $\chi^2(1, N = 76) = 4.86, p = .027$. Children in the sleep problem group had a higher rate of medication usage than the no sleep problem group, however, this difference was not significant. Table 5.5 displays the child descriptives across the two groups.

Table 5.4. Participants who Changed Their Mind Between Study 1 and Study 2 Regarding Whether Their Child had a Sleep Problem or not and Their Explanations.

Participant Number	Child's Age	Child's Diagnosis	Reason Given in Study 2 for why Child Does / Does Not Have a Sleep Problem
Sleep Problems in Study 1, but No Sleep Problem in Study 2 ($n = 8$) ^a			
22	6	DS	She goes to bed at 7.30 to 8.00 and wakes between 6.00 and 7.00 am. A little early in the morning, but she's an early bird like her dad
44	7	PDD	We sometimes have trouble getting him to sleep, but once he is asleep there is usually no problem unless he is ill
55	6	PDD	He's a pretty normal sleeper
108	11	ID	She sleeps well, wakes up with energy and will go to bed willingly. She may sleep more than regular 11.5 year old
146	8	ID	Because she had sleep problems when she was younger, now sleeps at night, not a very good sleeper, but much better than it was
181	13	ID	As he gets older he seems to be more relaxed and he is very active physically, which makes him tired and he is able to settle more easily at night
212	6	Oth ID	Not a sleep problem, breathing problem
223	6	ID	Doesn't like change and does like routine. It takes half an hour to put him to sleep at night in own bed. We cannot take him anywhere at night as he cannot sleep under any other conditions
No Sleep Problem in Study 1, but Sleep Problem Present in Study 2 ($n = 1$)			
174	15	DS	Has vivid, frightening dreams. Sometimes has trouble going to sleep, and wakes during night scared. Often needs light at night

PDD = Pervasive Developmental Disorder

ID = Intellectual Disability

Oth ID = Intellectual Disability due to medical condition

DS = Down's Syndrome

^a Three parents/carers did not provide a reason why they believe their child does not have a sleep problem.

Table 5.5. Descriptive Statistics for Gender, Diagnosis, Educational Placement, Medical Conditions, and Medication Use Across Groups.

Child Demographic	Sleep Problem Group (<i>n</i> = 20)		No Sleep Problem Group (<i>n</i> = 56)	
	<i>n</i>	(%)	<i>n</i>	(%)
Gender				
Male	11	(55)	40	(78.4)
Female	9	(45)	16	(28.6)
Diagnosis				
PDD	6	(30)	24	(42.9)
ID	3	(15)	15	(26.8)
DS	5	(25)	9	(16.1)
Oth ID	2	(10)	7	(12.5)
CP	3	(15)	1	(1.8)
PDD & CP	1	(5)	0	(0)
Education Placement				
SS	11	(55)	28	(50)
SDS	7	(35)	25	(44.6)
Combined SS and SDS	1	(5)	1	(1.8)
Early Intervention Centre	1	(5)	2	(3.6)
Medical Condition	13	(65)	23	(41.1)
Epilepsy	8	(40)	9	(16.1)
Asthma	2	(10)	5	(8.9)
Medication Use	11	(55)	21	(38.2)

PDD = Pervasive Developmental Disorder

CP = Cerebral Palsy

ID = Intellectual Disability

Oth ID = Intellectual Disability due to medical condition

PDD & CP = Pervasive Developmental Disorder and Cerebral Palsy

SS = Special School

SDS = Special Developmental School

5.3.5 BEDS Data for the Sleep Problem Group and the No Sleep Problem Group

The BEDS data for the 20 children whose parents/carers perceived their child to have a sleep problem was compared to the remaining 56 children whose parents/carers did not perceive their child to have a sleep problem (Table 5.6). A series of 2-tailed independent samples t-tests was performed to test for a significant difference between the mean factor scores, dyssomnia, parasomnia, and total scores for these two groups. The Sleep Facilitators factor was not included in this analysis

as it did not significantly fit the model in the confirmatory factor analysis procedure conducted by Schreck et al. (2003).

Table 5.6. Differences Between the Sleep Problem Group and No Sleep Problem Group on Sleep Characteristics as Measured by the BEDS: Mean Scores, Standard Deviations, and Independent Sample t-Test Results

BEDS Factor	Sleep Problem (<i>n</i> = 20) Mean (SD)	No Sleep Problem (<i>n</i> = 56) Mean (SD)	Test Score <i>t</i>	Significance <i>p</i>
Total	91.2 (31.4)	60.5 (26.0)	4.28	< .001
Dyssomnia	65.4 (21.0)	45.7 (19.8)	3.76	< .001
Parasomnia	28.4 (15.2)	16.0 (9.4)	4.25	< .001
Expressive Sleep Disturbances	6.9 (6.3)	1.8 (3.1)	3.49	.002
Sensitivity to the Environment	4.0 (3.7)	3.1 (3.1)	1.11	.27
Disoriented Awakening	4.6 (3.1)	4.4 (3.0)	0.18	.86
Apnoea	1.4 (1.8)	0.4 (1.0)	2.43	.02

Due to a violation of homogeneity of variance, analysis was performed based on unequal variances for the Expressive Sleep Disturbances Factor and the Apnoea Factor. A significant difference was obtained between the two groups on the Total score, Dyssomnia factor, Parasomnia factor, Expressive Sleep Disturbance Factor, and Apnoea Factor. No significant difference was found between children in the sleep problem group and those in the no sleep problem group for the Sensitivity to the Environment or the Disoriented Awakening Factors. The results from these analyses were used to assign children from the no sleep problem category into a third sleep group, those children who appear to have a sleep problem (as indicated by scores on the BEDS) but whose parents/carers do not recognise their child as having a sleep problem.

5.3.6 Allocating Children to the Sleep Problem Group where Parents/Carers do not recognise that a Sleep Problem Exists

Of the 56 children in the no sleep problem group, 21 (37.5%) were allocated to the group where the child was considered to have a sleep problem not perceived by the parent/carer. The majority of the children allocated to this group scored above the cut-off on more than one BEDS factor, however there were seven children allocated to this group who scored above the cut-off on one factor only: Four of these children scored above the cut-off on the Apnoea factor.

Thus three groups were formed, 20 children were in the sleep problem group (RSP) where the sleep problem was recognised by their parents/carer, 35 children were in the no sleep problem group (NSP), and 21 children were in the unrecognised sleep problem group (USP) where the child's sleep disturbance was not perceived as a problem by the parent/carer but appeared problematic in one or more domains. Appendix L and Appendix M depict the allocation of parents from the NSP group to the USP group.

5.3.7 Demographics of the Three Sleep Groups

The mean age of RSP children was 10.3 years ($SD = 3.7$), for NSP children it was 11.2 years ($SD = 4.8$), and for USP children the average age was 9.8 years ($SD = 4.3$). The USP children consisted of a higher proportion of males, had more children with a diagnosis of ID, experienced fewer medical conditions (specifically epilepsy, and ADHD), and had a lower number of children taking medication (Table 5.7). However, USP children were not significantly different from RSP or NSP children.

Table 5.7. Frequencies and Percentages of Child Characteristics Across Sleep Groups

Child Characteristic	Sleep Problem (<i>n</i> =20) <i>n</i> (%)	Unrecognised Sleep Problem (<i>n</i> =21) <i>n</i> (%)	No Sleep Problem (<i>n</i> =35) <i>n</i> (%)
Gender (<i>n</i> = 76)			
Male	11 (55.0)	16 (76.2)	24 (68.6)
Female	9 (45.0)	5 (23.8)	11 (31.4)
School Attended (<i>n</i> = 76)			
SS	11 (55.0)	9 (42.9)	19 (54.3)
SDS	7 (35.0)	11 (52.4)	14 (40.0)
Combination SS & SDS	1 (5.0)	0 (0.0)	1 (2.9)
Early Intervention Centre	1 (5.0)	1 (4.8)	1 (2.9)
Diagnosis (<i>n</i> = 76)			
PDD	7 (35.0)	7 (33.3)	17 (48.6)
ID	3 (15.0)	8 (38.1)	7 (20.0)
DS	5 (25.0)	3 (14.3)	6 (17.1)
Other ID	2 (10.0)	3 (14.3)	4 (11.4)
CP	3 (15.0)	0 (0.0)	1 (2.9)
Medical Condition (<i>n</i> = 76)			
Yes	13 (65.0)	8 (38.1)	15 (42.9)
Epilepsy	8 (40.0)	4 (19.0)	5 (14.3)
Asthma	2 (10.0)	3 (14.3)	2 (5.7)
Other	4 (20.0)	2 (9.5)	7 (20.0)
ADHD	2 (10.0)	0 (0.0)	1 (2.9)
Medication ^a (<i>n</i> = 75)			
Yes	11 (55.0)	7 (33.3)	14 (41.2)
No	9 (45.0)	14 (66.7)	20 (58.8)
That may impact on sleep	7 ^b (77.7)	3 ^c (75.0)	10 ^d (83.3)

SS = Special School; SDS = Special Developmental School

^a One parent/carer did not respond to the question regarding the child's medication use.

^b Two parents/carers did not specify the type of medication being taken.

^c Three parents/carers did not specify the type of medication being taken.

^d Two parents/carers did not specify the type of medication being taken.

5.3.8 Average Sleep Length Across the Three Sleep Groups

As rated by parents/carers, RSP children slept an average of 7.9 hours ($SD = 2$) per night, while NSP children slept an average of 9.5 hours ($SD = 1.0$) per night, and USP children slept an average of 10 hours ($SD = 1.3$) per night. The test for homogeneity of variance was violated ($p < .01$), therefore a power transformation was conducted and a significant overall effect was found, $F(2, 73) = 7.33, p = .001$,

$\eta^2 = .17$. Subsequent post-hoc tests revealed significant differences between the RSP group and the NSP group, $p = .035$, and the RSP group and the USP group, $p = .001$.

Furthermore, RSP children had slept an average of 8.2 hours ($SD = 2.3$) in the last 24 hours, while NSP children had slept an average of 10 hours ($SD = 1.9$), and USP children had slept an average of 10.1 hours ($SD = 2.2$) in the past 24 hours. A significant overall effect was obtained, $F(2, 73) = 6.3$, $p < .01$, $\eta^2 = .15$. Subsequent post-hoc tests revealed significant differences between the RSP group and the NSP group, $p < .01$, and the RSP group and the USP group, $p = .01$.

5.3.9 Child Daytime Behaviour

Children in the three sleep groups were compared on overall behaviour, as well as the five factor scores of the DBC and the five exploratory factors related to specific psychiatric syndromes (Table 5.8). A Single-factor between subjects ANOVA was performed on the total score, while a multivariate ANOVA was conducted on the five factor scores, and a Single-factor between subjects ANOVA with an adjusted alpha level (.01) was performed for each of the psychiatric syndrome factors. A significant difference was not obtained between the three sleep groups.

5.3.10 Child Adaptive Behaviour

Adaptive Behaviour of the children in the three sleep groups was compared using the nine factors of the ABAS as well as the total scaled score. As the ABAS provides scaled scores for children aged five years and above, the nine children under five years of age were not included in this analysis. A Single-factor between

subjects ANOVA was performed on the total score, while a multivariate ANOVA was conducted on the factor scores. No difference was found between the three sleep groups on adaptive behaviour (Table 5.9).

Table 5.8. Comparisons of Child Daytime Behaviour across the Three Sleep Groups

Behaviour Factor	RSP (<i>n</i> =20) <i>M</i> (<i>SD</i>)	USP (<i>n</i> = 21) <i>M</i> (<i>SD</i>)	NSP (<i>n</i> = 35) <i>M</i> (<i>SD</i>)	<i>p</i>
Total	52.8 (25.1)	47.9 (21.7)	43.5 (22.5)	.21
Factor Scores				
Disruptive	13.4 (7.9)	13.9 (9.2)	10.4 (7.7)	.24
Self-Absorbed	22.4 (10.6)	17.5 (9.9)	15.5 (10.3)	.06
Communication				
Disturbance	5.7 (4.5)	5.4 (3.8)	6.7 (4.6)	.52
Anxiety	5.2 (3.3)	4.9 (2.7)	3.7 (3.0)	.14
Social Relating	4.9 (2.8)	4.3 (3.3)	4.5 (2.9)	.83
Psychiatric Syndromes				
Autism Screening	20.5 (11.3)	16.7 (8.9)	15.6 (9.9)	.23
Depression	5.6 (2.5)	3.5 (2.5)	2.6 (2.4)	.00
Psychosis	0.4 (1.1)	0.5 (0.8)	0.6 (0.8)	.65
Hyperactivity	6.4 (3.6)	6.0 (3.3)	4.6 (3.2)	.14
Anxious Behaviour	3.4 (3.4)	3.2 (2.4)	2.8 (2.4)	.72

Table 5.9. Comparisons of Child Adaptive Behaviour across the Three Sleep Groups

Adaptive Behaviour Factor	RSP (<i>n</i> =19) <i>M</i> (<i>SD</i>)	USP (<i>n</i> = 17) <i>M</i> (<i>SD</i>)	NSP (<i>n</i> = 31) <i>M</i> (<i>SD</i>)	<i>p</i>
Total Scaled Score	14.4 (9.5)	22.0 (19.9)	21.3 (17.9)	.30
Communication	1.3 (1.2)	2.1 (2.5)	2.5 (2.2)	.45
Community Use	1.7 (1.9)	2.5 (2.7)	2.0 (2.2)	.53
Functional Academics	1.2 (0.5)	2.3 (2.6)	2.3 (2.5)	.36
Home Living	1.7 (1.7)	2.0 (1.8)	2.1 (2.2)	.61
Health & Safety	1.7 (1.7)	2.2 (2.2)	2.4 (2.5)	.69
Leisure	2.3 (1.9)	3.6 (3.4)	3.3 (2.8)	.32
Self Care	1.7 (1.6)	2.3 (2.7)	2.5 (2.6)	.48
Self Direction	1.4 (1.0)	2.1 (2.1)	1.8 (2.1)	.44
Social	1.5 (1.1)	3.0 (3.5)	2.4 (2.2)	.11

5.3.11 Parent Perceived Control Over Sleep and Daytime Behaviour

On average, RSP parents rated themselves as having less control over their child's sleep behaviour ($M = 3.7$ cms, $SD = 2.1$) compared to NSP parents ($M = 7.4$ cms, $SD = 2.3$), and USP parents ($M = 6.6$, $SD = 2.3$). This result was significant, $F(2, 73) = 17.6$, $p < .001$, $\eta^2 = .33$. Subsequent post-hoc tests revealed that the RSP parents yielded lower ratings of perceived control over sleep behaviour compared to the other two sleep groups, $p < .001$.

For control over daytime behaviour, RSP parents had a lower perceived control on average ($M = 4.7$, $SD = 2.4$), than NSP parents ($M = 6.7$, $SD = 2.6$), and USP parents ($M = 5.8$, $SD = 2.9$). This result was found to be significant, $F(2, 73) = 3.64$, $p = .031$, $\eta^2 = .091$. Post-hoc tests revealed a significant difference between the RSP parents and NSP parents, $p = .024$. Table 5.10 also compares the perceived control results across the three sleep groups in this study with those reported by Wiggs and Stores (1998b). Results for control over the child's sleep behaviour were similar across the two studies.

Table 5.10. Perceived Control Across Sleep Groups Compared with Results from a Previous Study (medians, and 10th-90th percentiles).

Perceived Control Rating	RSP Group		USP Group		NSP Group	
	Mode	(10 th -90 th %ile)	Mode	(10 th -90 th %ile)	Mode	(10 th -90 th %ile)
Sleep Behaviour						
Study 2	3.1	(1.0-6.2)	7.5	(2.6-8.8)	8.2	(3.1-9.8)
Wiggs & Stores*	2.9	(0.8-8.1)	7.7	(1.6-10)	9.0	(3.7-10)
Daytime Behaviour						
Study 2	4.2	(1.3-8.1)	7.1	(1.3-9.3)	7.3	(2.2-9.2)
Wiggs & Stores*	6.2	(0.1-9.3)	7.9	(1.0-10)	7.8	(0.5-10)

* Scores converted from millimetres to centimetres.

5.3.12 Parent Personality

A series of ANOVAS were used to compare the mean sleep group scores on the personality scales. There were no significant differences between ratings on parent personality dimensions across the groups (Table 5.11). Scores across the sleep groups on extraversion, neuroticism, and psychoticism were similar to those reported by Eysenck and Eysenck (1991), however, on average parents tended to score higher on the lie scale.

Table 5.11. Comparisons of Parent Personality Traits Across the Sleep Groups.

Personality Scale	RSP Group (<i>n</i> = 20)		USP Group (<i>n</i> = 21)		NSP Group (<i>n</i> = 35)		<i>p</i>
	Mean	(<i>SD</i>)	Mean	(<i>SD</i>)	Mean	(<i>SD</i>)	
Extraversion	7.8	(2.9)	6.1	(4.1)	6.1	(3.8)	.24
Neuroticism	4.8	(2.9)	5.0	(3.2)	5.0	(3.1)	.95
Psychoticism	3.0	(2.2)	1.5	(1.1)	1.9	(1.7)	.02
Lie	6.2	(3.2)	5.2	(2.5)	5.6	(3.0)	.55

Average scores reported for 878 females aged between 16-70 years (Eysenck & Eysenck, 1991): Extraversion (*M*=7.6, *SD*=3.3), Neuroticism (*M*=5.9, *SD*=3.1), Psychoticism (*M*=2.4, *SD*=1.9), Lie (*M*=3.7, *SD*=2.5).

5.3.13 Parental Stress

Parents from the three sleep groups obtained similar scores on the hassles scale (Table 5.12). A series of ANOVAS were conducted to compare the sleep groups on parenting hassles. There was no significant difference between the sleep groups on parental stress.

5.3.14 Locus of Control

Comparisons on the locus of control measure were conducted using ANOVAS. Parents in the sleep groups did not differ significantly on locus of control

ratings (Table 5.13). All groups scored higher on powerful others and chance locus of control than the average scores reported by Levenson (1972).

Table 5.12. Comparisons of Parental Stress Across the Three Sleep Groups

Parental Hassles Scale	RSP (<i>n</i> = 20) Mean (<i>SD</i>)	USP (<i>n</i> = 21) Mean (<i>SD</i>)	NSP (<i>n</i> = 35) Mean (<i>SD</i>)	<i>p</i>
Total Hassles	121.9 (35.4)	119.9 (31.0)	115.1 (32.2)	.57
Child Behaviour/Needs*	66.7 (22.0)	67.3 (19.0)	61.9 (19.7)	.36
Parental Needs	44.4 (13.1)	43.6 (14.1)	42.7 (14.3)	.91
Child Development	10.9 (5.4)	9.0 (3.6)	10.6 (4.1)	.31

Average scores reported at pre-test for 26 mothers in the control group from Hudson et al. (2003): Child behaviour/needs ($M=72.2$), parental needs ($M=42.6$).

*Scale has two sleep related items removed

Table 5.13. Comparisons of Locus of Control Across the Three Sleep Groups

Locus of Control Scale	RSP (<i>n</i> = 20) Mean (<i>SD</i>)	USP (<i>n</i> = 21) Mean (<i>SD</i>)	NSP (<i>n</i> = 35) Mean (<i>SD</i>)	<i>p</i>
Internal	32.8 (6.1)	33.8 (4.7)	34.0 (5.1)	.69
Powerful Others	15.4 (7.0)	18.1 (6.5)	15.6 (7.6)	.37
Chance	16.6 (7.4)	19.0 (7.9)	15.7 (8.1)	.32

Average scores reported by 51 females (Levenson, 1972): Internality ($M=35.5$, $SD=7.4$), powerful others ($M=14.6$, $SD=6.9$), chance ($M=13.4$, $SD=9.1$).

5.3.15 Parental Satisfaction and Efficacy

The difference between the sleep groups on scores of satisfaction in the parenting role, and perceived level of management within the parenting role were measured using ANOVAS. A significant difference across the groups was not obtained (Table 5.14). The average scores obtained for the sleep groups were similar to those reported by Johnston and Mash (1989).

Table 5.14. Comparisons of Parental Sense of Competence Across Sleep Groups

Parental Scale	RSP (<i>n</i> = 20) Mean (<i>SD</i>)	USP (<i>n</i> = 21) Mean (<i>SD</i>)	NSP (<i>n</i> = 35) Mean (<i>SD</i>)	<i>p</i>
Total	64.0 (9.1)	63.3 (9.6)	64.9 (11.9)	.86
Satisfaction	36.5 (6.0)	37.7 (7.3)	37.1 (7.8)	.88
Efficacy	27.5 (5.6)	25.7 (5.7)	27.8 (5.7)	.40

Average scores reported by mothers for 75 boys aged between 7-9 years (Johnston & Mash, 1989): Total ($M=62.5$, $SD=9.7$), satisfaction ($M=37.7$, $SD=6.1$), efficacy ($M=24.8$, $SD=5.8$).

5.3.16 Predicting Sleep Group Membership

A multinomial logistic regression analysis was performed to predict group membership to the three sleep groups. The predictors were: Diagnosis (PDD, ID, DS, Oth ID, CP), presence of a medical condition (yes, no), presence of epilepsy (yes, no), presence of ADHD (yes, no), use of medication (yes, no), estimation of how many hours sleep the child had per night, and the child's sleep length in the past 24 hours, as well as parental perceived control over the child's sleep and daytime behaviour. Data from 75 participants were available for analysis. Overall the first function of the regression model was significant, $\chi^2 (18 = 53.6)$, $p < .001$, indicating that the predictors as a set reliably distinguished between the RSP, USP, and NSP groups. The variance was moderate, with Nagelkerke's R square = .51. Prediction success was moderate, with 90% of RSP parents/carers, 64.7% of NSP parents/carers, and 61.9% of USP parents/carers correctly classified, for an overall success rate of 70.7%. Perceived control over the child's sleep behaviour, and the rating of how many hours the child slept per night were the most important function predictors.

5.3.17 Sleep Group Analysis of Child and Parent Variables Among Disability Types

The differences across the three sleep groups on the child and parent variables were independently examined for the three main developmental disorders present in the sample (PDD=30, ID=18, DS=14). Table 5.15 shows the descriptive statistics for each of the developmental disorder groups. Due to the small sample size for each of the three developmental disorders, nonparametric tests were used to analyse these data. A series of Kruskal-Wallis tests was performed, and multiple comparisons were made using Mann-Whitney tests with a Bonferroni adjusted alpha level ($\alpha < .017$).

For the children with a diagnosis of PDD, a significant effect was obtained between the three sleep groups for the DBC total score, the self-absorbed subscale, the autism subscale, the depression subscale, and the hyperactivity subscale of the DBC. Multiple comparison tests were performed where significant effects were found. A significant difference between the sleep problem group and the no sleep problem group was obtained for the DBC total score ($p = .007$), the self-absorbed subscale ($p = .001$), along with the autism ($p = .003$) and depression subscales ($p = .001$). While for the hyperactivity subscale a significant difference was found between the sleep problem group and the no sleep problem group ($p = .003$), as well as the sleep problem group and the unrecognised sleep problem group ($p = .007$).

For the children with a diagnosis of DS a significant difference was found between the three sleep groups for parental ratings of perceived control over the child's sleep behaviour. Multiple comparison tests revealed a significant difference between the RSP group and the NSP group ($p = .004$). No other significant effects were obtained between the three sleep groups in relation to child or parent variables.

For the children with a diagnosis of ID with unknown aetiology no significant effects were obtained between the three sleep groups in relation to child or parent variables.

Table 5.15. Descriptive Statistics for Gender, Diagnosis, Educational Placement, Medical Conditions, and Medication Use Across Groups.

Child Demographic	RSP	USP	NSP
	PDD		
Average Age (SD) n = 30	9.1 (3)	8.9 (3.5)	8.5 (3.8)
Gender n = 30 (%)			
Male	5 (83.3%)	5 (71.4%)	12 (70.6%)
Female	1 (16.7%)	2 (28.6%)	5 (29.4%)
Education Placement n = 30 (%)			
SS	3 (50%)	1 (14.3%)	11 (64.7%)
SDS	3 (50%)	6 (85.7%)	5 (29.4%)
Combined SS and SDS	0	0	0
Early Intervention Centre	0	0	1 (5.9%)
Medical Condition n = 30 (%)	4 (66.7%)	3 (42.9%)	5 (29.4%)
Medication Use n = 30 (%)	3 (50%)	3 (42.9%)	7 (41.2%)
	ID		
Average Age (SD) n = 18	9.9 (1.9)	8.2 (4.4)	12.2 (5.7)
Gender n = 18 (%)			
Male	1 (33.3%)	6 (75%)	4 (57.1%)
Female	2 (66.7%)	2 (25%)	3 (42.9%)
Education Placement n = 18(%)			
SS	1 (33.3%)	4 (50%)	1 (14.3%)
SDS	1 (33.3%)	4 (50%)	6 (85.7%)
Combined SS and SDS	1 (33.3%)	0	0
Early Intervention Centre	0	0	0
Medical Condition n = 18 (%)	3 (100%)	2 (25%)	5 (71.4%)
Medication Use n = 18 (%)	3 (100%)	2 (25%)	4 (57.1%)
	DS		
Average Age (SD)	10.8 (5)	11.8 (6.1)	14.5 (4.4)
Gender n = 14 (%)			
Male	2 (40%)	3 (100%)	3 (50%)
Female	3 (60%)	0	3 (50%)
Education Placement n = 14 (%)			
SS	3 (60%)	3 (100%)	3 (50%)
SDS	1 (20%)	0	2 (33.3%)
Combined SS and SDS	0	0	1 (16.7%)
Early Intervention Centre	1 (20%)	0	0
Medical Condition n = 14 (%)	1 (20%)	1 (33.3%)	2 (33.3%)
Medication Use n = 14 (%)	1 (20%)	0	2 (33.3%)

5.4 Discussion

The aim of Study 2 was to determine the influence of child and parent factors on parental perceptions or recognition of sleep problems in children with an ID. The first hypothesis that compared to RSP parents USP parents would report lower problematic daytime and adaptive behaviour was not supported. USP parents reported slightly lower scores in relation to child behaviour but these differences were not significant. For adaptive behaviour the USP parents reported slightly higher scores. The second hypothesis, that USP parents would report less stress was not supported. The three sleep groups obtained similar scores in relation to parent hassles. Hypothesis three, that USP parents would report significantly higher levels of perceived control over the child's sleep and daytime behaviour was supported. For perceived control over sleep behaviour, USP and NSP parents reported significantly higher ratings compared to RSP parents. While for daytime behaviour, NSP parents reported significantly higher ratings compared to RSP parents, while the USP parents did not differ with scores that were intermediate between the two other groups.

The fourth hypothesis, that USP parents would report a higher level of parental competence was not supported. The three sleep groups did not differ on ratings of parental satisfaction or efficacy. Hypothesis five, that USP parents would report a higher internal locus of control was not supported. Ratings on internality did not differ across the sleep groups. While a significant difference was not obtained on the chance and powerful others external locus of control scales, the USP group obtained higher scores than the RSP and NSP groups. Hypothesis six, that USP parents would report a lower level of neuroticism, and a higher level of extraversion was not supported.

Significant differences were not found across the three sleep groups on any of the personality dimensions.

5.4.1 Problematic Daytime Behaviour and Adaptive Behaviour of the Child

In this study there was no difference between children in the three sleep groups on problematic daytime behaviour or adaptive behaviour. This contrasts with many studies in the literature that have found a strong association between adaptive behaviour, daytime behaviour and the presence of sleep problems in children with an ID (Didden et al., 2002; Patzold et al., 1998; Quine, 1991; Richdale et al., 2000; Wiggs & Stores, 1996a). However, it is worth noting that RSP children had a higher total behaviour problem score, and a lower total adaptive behaviour score compared to the NSP and USP children. Furthermore, RSP children tended to score higher on average for the behaviour subscales and lower on average for each of the adaptive behaviour factors. Thus a trend was found between sleep problems, poorer adaptive behaviour, and higher problematic daytime behaviour. This trend is supportive of the findings by Wiggs and Stores (1998b) that indicate parents who do not recognise their child's sleep as problematic report significantly less child daytime behaviour problems.

5.4.2 Parent Factors

The RSP group displayed significantly lower levels of perceived control over their child's sleep behaviour as opposed to the NSP and USP groups. The RSP group also displayed significantly lower perceived control over their child's daytime behaviour compared to the NSP group, but not compared to the USP group. These results support the findings of Wiggs and Stores (1998b), where parents who had a

child with an unrecognised sleep problem reported higher ratings of perceived control. The authors suggested that perceived control may act as a protective factor against stress. This view has been proposed by Lazarus (1966) and supported by research conducted in other stress-invoking situations (Doering et al., 2000; Langer et al., 1975; Moser & Dracup, 1995).

However, surprisingly there was no significant difference between the sleep groups for stress. The lack of association between perceived control and stress in this study indicates that perceived control may not act as a stress mediator, but instead has a direct influence on whether or not parents consider their child to have a sleep problem.

Similarly, having an internal locus of control has been associated with lower levels of parental stress (Friedrich et al., 1985; McKinney & Peterson, 1987; Mouton & Tuma, 1988; Rimmerman, 1991). Wiggs and Stores (1998b) could not draw any firm conclusions from their study in relation to locus of control, but they did report a trend whereby parents in the sleep problem group scored higher on external locus of control. In this study it was hypothesised that parents in the USP group would display a higher internal locus of control compared to the RSP group. This was not found to be the case, with USP parents tending to report higher external scores, suggests that sleep problem perception is not related to general locus of control.

The current study was the first to have considered the parent personality factors of extraversion and neuroticism in relation to sleep problems in children with an ID. In a study on TD children Gelman et al. (1998) reported that mothers who had a child with a sleep problem were significantly more introverted or neurotic than control mothers. In this study no difference was obtained between parents on scores

of extraversion or neuroticism, however, all three sleep groups scored higher than average on the lie scale with parents in the RSP group scoring highest on this scale.

The children in the sleep problem group were rated by parents as having significantly less sleep per night than the children without sleep problems and the children who had a sleep problem that was not perceived by their parents. This suggests that children who have a sleep problem that is not perceived by their parents may have a sleep disturbance that is less severe and less disruptive than that of children with a recognised sleep problem. Alternatively, higher parent estimations of the child's sleep length could also indicate that the parent's sleep is less disturbed by their child. This view is somewhat different to that expressed by Wiggs and Stores (1998b) who reported that parents who did not perceive their child's sleep problem still recognised their child's sleep as unsatisfactory. An alternative explanation might be that other factors such as perceived control over the child's sleep behaviour have an influence on these parents when subjectively rating their child's sleep time. Therefore, parents who perceive themselves as having more control over the sleep behaviour may be more likely to overestimate their child's sleep time, and vice versa.

5.4.3 Change of Sleep Problem Perception over time

In the time that elapsed between Study 1 and Study 2, twelve participants changed their answers in relation to sleep problem perception. Eleven participants did not consider their child to have a sleep problem in Study 2, however, in Study 1 they did perceive their child to have a sleep problem. Also, one participant thought their child did not have a sleep problem during Study 1 but reported a sleep problem

in Study 2. The child's age, diagnosis, and duration of the sleep problem did not seem to influence this change in opinion of these parents/carers.

While it is possible that these parents obtained some form of treatment for their child's sleep problem, none of the parents made any reference in relation to receiving help for their child's sleep problem in their explanation of why they thought their child did not have a sleep problem. It is also possible that the child's sleep may have changed for the better during the interval between the two studies. Two parents reported that their child's sleep was better than when the child was younger, however, it was not possible to tell if the improvement occurred during the interval between the two studies. Alternatively, these parents may have been more accepting of their child's difficult sleep behaviour, and had worked out ways of managing the problem so that it no longer disturbed them enough for it to be considered a sleep problem. Another possibility is that in the time that expired between Study 1 and Study 2 these parents/carers may have become more focused on other behavioural issues and the child's sleep was no longer a prevalent concern.

The fact that twelve parents in this Study changed their mind regarding whether or not their child had a sleep problem indicates that for some parents perception of a child sleep problem is not stable. For these parents it would seem that sleep problem perception is influenced by transient factors instead of stable protective factors as suggested by Wiggs and Stores (1998b).

5.4.4 Diagnosis Specific Results

For the PDD group alone, parents in the RSP group reported that their children had significantly higher scores for total behavioural disturbance, self-absorbance, symptoms of autism, hyperactivity, and depression as compared to the

NSP group. For hyperactivity, the RSP group reported significantly higher scores compared to both the NSP group and the USP group. For children with Down syndrome, parents in the RSP group reported significantly lowered perceived control over the child's sleep behaviour compared to parents in the NSP group. For the children with an ID of unknown aetiology no significant effects were found between the three sleep groups..

The findings for the three diagnostic groups show considerable variation in relation to the overall results as well as each other. Therefore, as has been previously suggested, it appears that the diagnostic composition within a heterogeneous study can affect the results obtained (Didden & Sigafos, 2001). This would account for the differences that have been reported across many studies that have considered prevalence rates and associations between various child and parent factors in relation to child sleep problems. The different findings obtained across the three diagnostic groups adds further support for conducting sleep studies that are diagnostically specific (1992). The medical conditions of the children should also be taken into consideration. In the current study children in the RSP group had a higher occurrence of epilepsy compared to the other two groups.

5.4.5 Study Limitations

The limitations of Study 2 should be taken into consideration when interpreting the findings of the study. The small number of parents/carers involved in this study was a clear limitation, particularly when participants were then further categorised into one of three sleep groups. The considerable age range and diagnostic heterogeneity of the children in this study is a further limitation of note. While results specific to diagnosis were investigated, the numbers for each disability

type was low across the three sleep groups. These limitations are often difficult to avoid; gaining participants in this area of research is not easy. While the 79% response rate in Study 2 is very acceptable, one must remember that these participants constituted approximately 31% of participants from Study 1, while Study 1 itself only had a 30% return rate. Therefore, these results are based on a small sample and may not be reflective of this population at large.

A further limitation of the Study was that 20 parents did not provide an explanation of why they thought their child had/did not have a sleep problem. These explanations were a valuable source of data, as many of the parents who did not consider their child to have a sleep problem clearly reported sleep difficulties in their explanations. Thus, parent explanations may be an effective means of categorising parents into the RSP, NSP, and USP groups. As not all participants completed this question it meant that the explanations could not be used to categorise parents.

5.4.6 Summary and Conclusions

The results of this study indicate that there are differences between parents who do and do not perceive their child's sleep problem. These differences lie in the amount of sleep the child has, and parental perceived control over the sleep behaviour. Previous research has associated perceived control with moderation of stress. However, in this study perceived control was associated with sleep problem perception in the absence of an association between stress and sleep problems in children with an ID. Thus, for parents who do recognise their child's sleep problem, there may be other factors that serve to reduce their perceived control over the child's sleep behaviour. Parents who have a child with an ID and a sleep problem have been known to attribute the sleep behaviour to other causes, believe the

problem is permanent and cannot be treated, or think the problem is related to the child's disability (Bramble, 1996; Robinson & Richdale, 2004; Stores, 2001a). Such factors may prevent parents from seeking access to sleep interventions and could lead to a reduction of perceived control over the child's sleep behaviour. Alternatively, for parents who do not perceive their child's sleep problem there may be other factors that serve to increase their perceived control over the child's sleep behaviour. Greater sleep time of the child, and different attitudes or beliefs about the child's sleep may give these parents a heightened sense of control over the child's sleep behaviour.

Parent perception of a sleep problem is also an important issue as it has a direct influence on whether or not parents will seek help for their child's sleep problem. Many parents have a child with an ID and a sleep problem but do not perceive their child's sleep to be an issue that requires professional intervention. Thus, many parents and children will be unnecessarily enduring long-term sleep problems and the associated negative effects. This study supported the finding of Wiggs and Stores (1998b) confirming the importance of parent perception for sleep problems in children with an ID, and the role of perceived control over the child's sleep problem.

The current study did not obtain similar findings to that of Wiggs and Stores (1998b) in relation to the role of child behaviour and parent stress for sleep problem perception. However, differences across the studies need to be considered when comparing the findings. Apart from perceived control ratings, different measures were used, and a different process was used to categorise parents/carers into the USP group. This study used the BEDS which has been created from distinct ICSD (ASDA, 1992) diagnostic criteria for parasomnias and dyssomnias that occur during

childhood. Thus, the current study considered all types of childhood sleep problems, whereas Wiggs and Stores (1998b) focused solely on night settling, night waking, and early waking sleep problems.

Further research is warranted in order to advance understanding on this issue. Asking parents to explain why they thought their child did/did not have a sleep problem provided useful information in this study, and through parent interviews could be expanded upon in future research. Conducting follow-up interviews approximately 3-6 months apart would also be a useful way to ascertain what factors influence some parents to change their perception regarding whether or not their child has a sleep problem.

CHAPTER 6. STUDY 3: A GENERAL PARENT TRAINING PROGRAM FOR THE BEHAVIOIRAL MANAGEMENT OF SLEEP PROBLEMS FOR CHILDREN WITH AN ID

6.1 Study Rationale, Aims, and Hypotheses

Research to date indicates that night settling, waking, co-sleeping and early morning waking problems in children with an ID are a common occurrence, are long lasting, and are associated with other areas of functioning such as child daytime behaviour problems, maternal stress, and depression (Didden et al., 2002; Quine, 1991; Quine, 2001; Richdale et al., 2001; Wiggs & Stores, 1996a; Wiggs & Stores, 1998b). For children with an ID, sleep problem intervention utilising the behavioural principle of extinction is considered a probably efficacious treatment (Richdale & Wiggs, 2005). In assessing the efficacy of behavioural intervention only a few studies have considered the impact on child and parent factors associated with sleep problems in children with an ID.

Using rapid extinction to treat the chronic sleep problems of 15 children with an ID Bramble (1997) found significant improvements in child daytime behavioural problems, as well as maternal stress and maternal sleep quality. In their sleep intervention study, Wiggs and Stores (1999) also reported improvement in parental stress, maternal sleep quality, and perceived control over the child's sleep, however, behavioural improvements occurred for both the intervention group and the control group. Subsequent studies have used extinction and other behavioural principles to successfully treat sleep problems in children with an ID, and have reported little to no associated improvement in child daytime behaviour, or maternal stress (Thackeray & Richdale, 2002; Weiskop, 2001). Weiskop stated that a lack of

improvement in child daytime behaviour indicated that the parents did not generalise the sleep intervention skills across setting and child behaviour. Although her sleep intervention program employed strategies to facilitate generalisation, it appears the intervention was too sleep-specific for this to occur.

Thus, the aims of Study 3 were to:

1. Using sleep as a training exemplar, examine whether a behaviour intervention program for parents of children with an ID and both difficult behaviour and sleep problems was an effective intervention for sleep problems in children with an ID.
2. Determine if this intervention program led to an improvement in child daytime behaviour.
3. Assess whether participation in the intervention program was associated with change in relation to parental perceived control over the child's sleep and daytime behaviour, confidence in parenting ability, as well as parent hassles.

It was hypothesised that:

1. The intervention program would lead to parental report of sleep problem reduction.
2. The intervention program would lead to parental report of improved daytime behaviour.
3. The intervention program would lead to parental report of an increase in perceived control over the child's sleep and daytime behaviour, as well as greater confidence in parenting ability, and a decrease in the report of parent hassles.

6.2 Method

6.2.1 Participants

The mothers of five children with an ID and sleep problems who participated in Studies 1 and 2 participated in Study 3. All of the participants lived in metropolitan Melbourne, spoke English as their primary language, and had a child with an ID who exhibited at least one of the following sleep problems: Co-sleeping, night settling, night waking, or early waking. Four of the children were males and one was female, with a mean age of 8 years, 6 months (range = 5 years, 1 month to 12 years, 3 months). Three of the children had a pervasive developmental disorder, one child had Down syndrome, and one child had a chromosomal abnormality. Three of the children had epilepsy, two had ADHD, one had asthma, and three of the children were taking medication. Two of the children attended a special developmental school (for children with an IQ less than 50), while one attended a special school (for children with an IQ between 50 – 70), one attended a combined special and special developmental school, and one child attended an early intervention centre. Three of the children in Study 3 were only children, while one child had a younger sibling, and one child had two younger siblings (Table 6.1).

For all five families only the mother participated in Study 3. Three of the five children lived in two-parent families while the remaining two children lived in single-parent families with the mother. Two of the mothers had a tertiary level of education, while three mothers had completed secondary school, and three of the mothers worked outside the home (Table 6.2). One mother had Multiple Sclerosis and was confined to a wheelchair.

Table 6.1 Demographic Information of Children in Study 3.

Participant	Id Number from Study 1 and 2	Age	Gender	Primary Diagnosis	Other Diagnoses	Medication	School Attended	Level of ID	Mode(s) of Communication	Siblings
1	3	9 yrs, 11 mths	Male	Autism	ADHD, Asthma	Flixotide, Ventolin, Haloperidol, Vallergan on occasion	SDS	Assessed as moderate	Speech and signing	None
2	61	12 yrs, 4 mths	Male	Autism	ADHD, Epilepsy	Thioridazine, Dexampheta- mine, Vallergan on occasion	SS	Assessed as mild	Speech and signing	None
3	117	8 yrs, 11 mths	Female	Chromosome abnormaltiy 8Q	Epilepsy	--	SDS	Assessed as moderate	Signing and electronic communication device	None
4	227	8 yrs, 5 mths	Male	PDD NOS	Epilepsy, Verbal dyspraxia	Lamictal Vallergan on occasion	SS / SDS	Assessed as mild	Speech, signing, electronic communication board, and electronic communication device	Sister aged 6, brother aged 3
5	244	5 yrs, 2 mths	Male	Down syndrome	--	--	EI	Mild, not formerly assessed	Speech	Sister aged 3

SS = Special School; SDS = Special Developmental School; SS / SDS = Special School and Special Developmental School combined; EI = Early Intervention Centre.

Table 6.2 Demographic Information of Parents in Study 3.

Participant	Id Number From Study 1 and 2	Mother's Level of Education	Mother's Occupation	Father's Level of Education	Father's Occupation
1	3	Tertiary	Home duties	*	*
2	61	Completed Secondary	Occupational therapist assistant	*	*
3	117	Completed Secondary	Home duties	Completed Yr. 8	Forklift driver
4	227	Tertiary	Fitness instructor	Tertiary	Stockbroker
5	244	Completed Secondary	Administration officer	Completed secondary	Disability worker

* Single parent

6.2.2 Materials

6.2.2.1 Demographic Information

A family information sheet was used to obtain demographic information including the primary language spoken at home, highest level of schooling completed by the child's parent, the parent's occupation as well as partner's occupation, and the participant's relationship to the child. The child's date of birth, gender, type of school attended, diagnosis, and presence of any medical conditions were also recorded. The child's level of ID (whether formally assessed or estimated) and modes of communication were also ascertained.

6.2.2.2 Sleep Information

Parents completed a sleep questionnaire, The BEDS (Schreck, 1997/1998; Schreck, Mulick, & Rojahn, 2003). This questionnaire was used in Study 2 and is outlined in section 5.2.2.2. Parents also completed two sleep diaries, one in relation

to the child's sleep (adapted from Patzold, Richdale, & Tonge, 1998) and one that focused on the parent's sleep (Appendix N). Throughout the study, both sleep diaries were completed on a daily basis and consisted of evening questions and morning questions. To avoid confusion the child's sleep diary was printed on white paper while the parent's sleep diary was printed on green paper.

For the sleep diary relating to the child's sleep, nine evening questions considered whether the child was sleepy during the day or not; whether the child had slept during the day or not, and if so, where they fell asleep, the time and how long for. Medication use, dosage, and time were also reported, as well as whether the child followed a bedtime routine or not. Parents also reported what time the child went to bed, how sleepy the child was at this time, and if the child called out or got up before going to sleep. If the child did get up or call out, parents reported the time and reason for getting up/calling out, and their response to this. The final two evening questions related to the time the child actually fell asleep and where they were when they fell asleep.

Eight questions were completed in the morning in relation to the child's sleep from the previous night. These questions ascertained whether the child woke during the night. If the child did wake during the night then the parent was asked to report the time of waking, reason, what the child did, the parent's response and the approximate amount of time spent awake. Parents also rated how restless they thought their child's sleep was, whether the child slept in the parent's bed, and what time this occurred, the time of waking in the morning, and whether the child was woken by the parent or not. Parents then reported whether the child had been ill during the night, if there had been disruptions to the child's routine during the past 24 hours, and the nature of the disruptions. Finally, parents were asked to give an

overall rating of the child's sleep, and further comments about the child's sleep were provided if necessary.

Questions relating to the ratings of the child's sleep overall, how restless the child's sleep had been, and how sleepy the child was during the daytime and at night time used a 10 centimetre visual analogue scale. Extreme statements were anchored at each end of the scale and parents answered these questions by placing a cross on the line. Other questions required the parent to check a box or write in a short answer.

The parent sleep diary consisted of five evening questions where the parents were asked to rate their level of sleepiness during the daytime, if they had slept during the day, the location, start time and end time of any daytime sleep that occurred. Parents reported if they had taken any evening medications, the dosage and the time medication was taken. The parents then reported what time they turned the light out to go to sleep, and rated their level of sleepiness at this time.

Seven morning questions were completed by the parents including rating the level of difficulty in falling asleep, sleep onset, time of morning waking, and the number of hours slept per night. Parents were then asked if they woke during their sleep, and to rate the level of trouble getting back to sleep after having woken up. Finally, parents rated how restless their sleep had been, gave an overall rating of sleep for that night, and provided any further comments about their sleep if relevant.

Sleepiness ratings during the day and at night time, the level of trouble falling asleep and getting back to sleep, along with sleep restlessness ratings and the overall sleep rating were obtained using 10 centimetre visual scales with extreme statements anchoring each end. Other questions required the parent to check the relevant box or provide a brief written answer.

6.2.2.3 Child Behaviour Information

The Developmental Behaviour Checklist (second edition) – Primary Carer Version (DBC) (Einfeld & Tonge, 2002) was used to assess the level of emotional and behavioural disturbance of the children involved in the study. This questionnaire was used in Study 2 and is detailed in section 5.2.2.3.

6.2.2.4 Parent Information

The Parental Sense of Competence (PSOC) scale (Johnston & Mash, 1989) was used to consider parental efficacy and satisfaction, while the Parenting Hassles Scale (PHS) short form (Gavidia-Payne & Stoneman, 1997) was used to measure everyday stresses experienced by parents of children with an ID. Both of these questionnaires were used in Study 2 and are discussed in more detail in sections 5.2.2.6 and 5.2.2.7. Parental perceived control over any difficult sleep behaviour pattern displayed by their child, and their perceived control over any difficult daytime behaviour displayed by their child was assessed using a 10 centimetre visual analogue scale. Extreme statements of ‘not at all able to control it’ to ‘totally able to control it’ were anchored each end of the scale with high scores indicating greater perceived control. This measure of perceived control was used in Study 2 and has been used previously by Wiggs and Stores (1998b).

6.2.2.5 Social Validity

The Goal Achievement Scale (GAS) (Hudson, Wilken, Jauernig, & Radler, 1995; Matthews & Hudson, 2001) was used to assess the clinical significance of the change in the child’s sleep and daytime behaviour (Thackeray & Richdale, 2002;

Weiskop et al, 2005). The scale is used in relation to a specific target behaviour, and can be used for both behaviour excesses that need to be decreased as well as behaviour deficits that are to be increased. A baseline measurement of the behaviour is taken and represents zero percent success, indicating that no improvement in the behaviour occurs post-intervention. Before intervention commences the parent and trainer set a goal for improvement that constitutes 100% success. Parents are told the goal for 100% success should reflect a realistic expectation for improvement, and thus, does not have to mean total amelioration or total mastery of the behaviour. The GAS is a beneficial measure of social validity because it allows a researcher to compare intervention outcomes across participants on a range of different target behaviours.

Social validity of the intervention program was further assessed using a parent satisfaction questionnaire. This consisted of eight questions relating to the complete program, 14 questions relating to specific aspects of the program, and an additional comments section. The complete program questions were rated on a five point Likert scale where 1=*Strongly Disagree*, 2=*Disagree*, 3=*Not sure*, 4=*Agree*, 5=*Strongly Agree*. Scores could range from 5 to 40 with higher scores indicating a higher level of satisfaction with the program. The other comments section of questionnaire asked parents to make any additional comments about the program.

6.2.2.6 *The Signposts program*

The Signposts for Building Better Behaviour program (Hudson et al., 2003) aids families who have a child with an ID and who exhibit difficult behaviour. It is a general behavioural intervention program (not specific to sleep problems) that assists parents work out the purpose of their child's difficult behaviour. Parents are also

taught multiple strategies to promote positive behaviour in their children, as well as reducing difficult behaviours. Signposts also aims to help parents prevent difficult behaviour from developing in the future.

For therapists the signposts materials consist of a facilitator's manual comprising six sections. The first three sections contain information and guidelines for program delivery in one of three formats, groups of parents, individual families/telephone support, and individual families/self-directed. For Study 3 the Signposts program was delivered to parents using the group setting. For each mode of delivery the manual contains a description of the program including aims of the program and an outline of the training plan, process and product evaluation requirements, delivery guidelines including establishing groups, setting, equipment, resources, preparation, and conducting sessions, as well as a specific outline for each session. Section 4 of the facilitators manual contains relevant information sheets and measures, while Section 5 relates to answers to frequently asked questions from parents regarding the content or implementation of strategies. Section 6 of the manual consists of forms for photocopying.

For parents the signposts materials consist of eight information booklets, a videotape, and a workbook with exercises. The information booklets are titled:

1. Introduction
2. Measuring your child's behaviour
3. Systematic use of daily interactions
4. Replacing difficult behaviour with useful behaviour
5. Planning for better behaviour
6. Teaching your child new skills
7. Dealing with stress in the family

8. Your family as a team.

Information booklets 7 and 8 are adjunctive booklets to be completed by the parent when and if they think it necessary.

The workbook is used for parents to record their responses in relation to the material that is presented in the booklets and the video, and how this relates to their child. The video contains 33 short scenes demonstrating examples of the skills taught within each booklet. The video scenes contain TD children and children with Down's syndrome.

An evaluation of the Signposts program for reported improvements in child behaviour, as well as parent efficacy and stress. High levels of parent satisfaction with the program were reported (Hudson et al., 2003).

6.2.3 Procedure

The RMIT University Human Research Ethics Committee approved Study 3 (Appendix O).

6.2.3.1 Recruitment

Two methods of recruitment were used to gain participants for Study 3. The first involved participants from Study 2 who had a child with a sleep problem and indicated an interest in participating in Study 3 (all parents in Study 2 who rated their child as having a sleep problem were directed to a question that asked if they would like to be involved in Study 3). The second method of recruitment involved contacting (via email) the workers in the Northern region of the specialist children's service (department of human services) who had attended a training workshop on the Signposts program. Workers were asked to approach families where night settling,

night waking, early waking, or co-sleeping problems were currently an issue, and encourage them to participate in the research. The details of those families interested in participating were forwarded onto the researcher. The researcher then made telephone contact with all interested parents and outlined the nature of the research.

In total 17 parents expressed an interest in participating, 15 of these parents had been involved in Study 2 and 2 parents became involved through the specialist children's service. Of the 15 parents from Study 2 who were contacted by the researcher, 5 chose to participate in Study 3 while 8 chose not to participate and 2 parents were not eligible as their child did not have a sleep problem. The two parents who were contacted independent of Study 2 also chose not to participate in the study. Two participants chose not to participate due to the travel time involved, while one parent did not participate because she thought her child's sleep problem had greatly improved and no longer required treatment. Another parent chose not participate in Study 3 because she could not commit to the program over the time frame required, one parent was not able to participate due to current marital problems, while another parent had started seeing a psychiatrist in relation to her child's severe behaviour problems and did not have time to travel to, or participate in the research. Two parents did not give reasons for not participating, while for the remaining two parents the study was deemed inappropriate as the children did not exhibit night settling, waking, or co-sleeping problems.

Packages were mailed to the five parents who agreed to participate; they consisted of the questionnaires in conjunction with a plain language statement (Appendix P) that outlined the research, and a consent form (Appendix Q) to be completed by the participant. The researcher then contacted the parents via telephone

to clarify any questions and to explain how to complete the sleep diaries and questionnaires.

6.2.3.2 Intervention Program

The parents involved in Study 3 attended six, 2.5 hour sessions over a period of eight weeks. Typically sessions are conducted on a fortnightly basis, however, for the purposes of the research sessions two to five were conducted one week apart. All of the sessions were conducted at the RMIT psychology clinic, and were facilitated by the researcher and two psychology post-graduate students. The students were used as co-facilitators, with one student co-facilitating one Signposts group each. Both the researcher and the two students had satisfactorily completed a two-day training workshop in the implementation of the Signposts program. As part of his training, the researcher had also co-facilitated a Signposts program with one of the creators of the program.

The first session related to the information booklet “Measuring your child’s behaviour”, and taught parents how to clearly describe, measure, and record their child’s behaviour. Parents chose two target behaviours to record for the duration of the program. Behaviour one consisted of a behaviour that was desirable and that the parent wanted to increase (e.g., compliance), while behaviour two consisted of a difficult behaviour that the parent wanted to decrease (e.g., night waking). Parents were instructed that the difficult behaviour chosen needed to be in relation to the child’s sleep problem. Parents were then instructed to measure and record these two behaviours for two weeks onto observation charts that were contained in their workbook. These recordings became the baseline measure for the target behaviours chosen.

Session two was conducted two weeks later and related to the information booklet “Systematic use of daily interactions”. This session began with a review of the baseline behaviour recordings, and then parents set a goal for improvement on each of the two target behaviours (GAS). During this session parents also learned to identify their child’s strengths, understand the effects of triggers and consequences on a child’s behaviour, identify positive consequences for their child, how to use triggers and consequences to build on the child’s strengths, how to give effective instructions, and how to establish household rules in relation to behaviour. Parents were encouraged to provide additional opportunities for their child to use their skills, and to provide positive consequences, especially labelled praise, in response to appropriate behaviour. The parents were asked to think about whether they may have been unwittingly providing positive consequences for the sleep problem. Between sessions parents were also instructed to complete a triggers and consequences record sheet, a labelled praise monitoring form, and an instruction giving monitoring form that were contained in their workbooks.

Session three related to the booklet “Replacing difficult behaviour with useful behaviour” and began with a review of the homework from the previous session. Parents were then taught how to identify the purpose of their child’s difficult behaviour, and then developed a strategy to remove the child’s difficult behaviour (i.e. sleep problem). Parents were also taught to use negative consequences in relation to difficult behaviour. At the completion of this session, parents were instructed to apply the strategy to replace their child’s difficult behaviour. In their workbooks parents were provided with a form regarding the development of a plan for replacing difficult behaviour with useful behaviour, as well as time-out record sheet and a time-out monitoring form.

Session four related to the information booklet “Planning for better behaviour”, and began with a review of the homework from the previous session. Parents gave feedback on their strategy for replacing their child’s difficult behaviour and discussed the effectiveness of this strategy. Any problems were discussed and parents were encouraged to continue with their strategy. The remainder of the session focused on the development of daily routines for the management of child behaviour, identifying high-risk situations in the home and community setting, describing and teaching parents to develop a planned activities routine in relation to these high risk-situations. Parents described the sleep routine that they used for their child, and developed a planned activities routine in relation to their child’s sleep problem. At the end of the session parents were instructed to continue with their plan for replacing the difficult sleep behaviour, and to implement their planned activities routine over the coming week.

Session five related to the information booklet titled “Developing more skills in your child” and began with a review of the homework. Parents gave feedback on their plan for replacing the difficult sleep problem behaviour and the planned activities routine that they implemented for the sleep problem. The remainder of the session involved teaching parents to select appropriate skills to teach their child, set objectives for teaching new skills and indentify parts of a skill, how to use the teaching by showing method and the step by step teaching method, and how to negotiate and liase with others who are involved in teaching the child. Parents were instructed to continue implementing their plans and to attempt to teach their child a new skill. Parents were also instructed to continue with the behaviour recordings over the upcoming fortnight.

Session six was conducted two weeks later and was review session to check on progress and revise any strategies covered in the previous sessions if necessary. Advice on troubleshooting was also provided, and parents were encouraged for their effort and successes. Post-program measures were also completed during the session and goal achievement was revised.

During the two weeks between session 1 and 2, and session 5 and 6, the researcher had weekly phone contact with the parents to check on progress, allow parents to ask questions, and to encourage effort. Parents were also informed that they could contact the researcher if necessary. If participants missed a session, the information booklet was mailed out to the parent with instructions to complete the booklet and relevant exercises. A follow-up phone call was made to check on the parent's progress and revise any issues of concern expressed by the parent.

6.2.3.3 Follow-up

Six months after the completion of the program (session 6) the participants were contacted by the researcher, and the sleep diaries and questionnaires were mailed out to the participants. The sleep diaries and behaviour recordings were collected for two weeks and the questionnaires were completed and returned to the researcher. A two-hour follow-up session was then held for each group at the clinic. The format structure and session content for the follow-up session was the same as in session six.

6.2.4 Study Design

Study 3 was a multiple baseline design with fixed length phases across groups of participants. Parents who agreed to participate were randomly assigned to one of two groups with three participants allocated to group one and two participants allocated to group two. The study consisted of a baseline phase, an intervention phase and a follow-up phase. Participants in the two groups received the same intervention program delivered across the same number of sessions (Appendix R). The baseline phase and intervention phase ran for a total of 13 weeks across the two groups from August to November in 2002, while a 2-week follow-up was conducted six months after completion of the program, in April and May 2003. For the parents in group one, week one involved session one of the Signposts program where parents were taught how to describe, measure and record behaviour. Parents then performed data collection for two weeks, recording their child's behaviour as well as completing the child and parent sleep diaries. Weeks three to six contained the intervention phase, and weeks seven and eight involved post-intervention data collection.

For parents in group two, weeks one to five involved baseline data collection of the child and parent sleep diaries. In week six the parents completed session one of the Signposts program, and then collected baseline behaviour data for two weeks. Weeks eight to eleven consisted of the intervention phase, and weeks twelve and thirteen involved post-intervention and data collection.

6.2.5 Sleep Problem Descriptions

6.2.5.1 Participant 1

Participant one was mother to a 9-year-old male who had autism, ADHD, and asthma. She described her child as exhibiting bedtime refusal and settling difficulties, night waking, as well as early waking and co-sleeping. These sleep problems had persisted for the past two years, and were rated by the mother as being moderately severe. Of specific concern was the child's bedtime refusal that often led to temper tantrums and the child running away from his mother at bedtime, requiring her to physically take him into his bedroom. Often this led to the child being put into his mother's bed and transferred into his own bed when asleep. Consequently, night wakings led to the child calling out to his mother or appearing in her room and demanding to sleep in bed with her.

The child's mother had never sought professional help but used Vallergan when her child's behaviour was particularly difficult. As a result of this bedtime behaviour, the mother reported that her own sleep was being disrupted, and she was becoming increasingly frustrated with her child's sleep behaviour.

6.2.5.2 Participant 2

Participant 2 was the mother of a 12-year-old male who had autism, ADHD, and epilepsy. The parent stated that her child displayed settling difficulties, as well as night waking, and co-sleeping difficulties. These sleep problems were lifelong and rated as moderate in severity by the child's mother. The child's bedtime was variable, and he would sometimes fall asleep in places other than his own bed.

Child 2 also required a blanket to fall asleep in his own bed, and would often roll in his blanket when put into his bed. When night waking occurred the child

typically went to the toilet and then played in his room for up to one hour before re-settling to bed, or engaging in co-sleeping in his mother's bed. Vallergan was used occasionally and was rated as moderately successful, and the mother had also tried to keep her child up as late as possible so that he would go to bed in a tired state and would fall asleep quickly.

6.2.5.3 Participant 3

Participant 3 had an 8-year-old daughter with a chromosomal abnormality, and epilepsy. She reported her child as displaying early morning waking in conjunction with night waking, and co-sleeping. Sleep apnoea had also been an issue in the past but had been treated with surgery three years prior to participation in Study 3. The child's sleep problem started at age two years and was rated as moderate in severity. Of specific concern for this mother was the child's night waking that was followed by intense bouts of crying or screaming that would occur two to three times on a nightly basis. As a result, co-sleeping had also become an issue with the child sleeping in the mother's bed on a constant basis. Previous attempts at treatment included an operation for the child's sleep apnoea that was rated by the mother as being moderately successful, and herbal treatment prescribed by a natural therapist that was rated as highly successful. The mother had also spent a short period of time at an early parenting centre to help with sleep problems. This was rated as moderately successful. While these treatments appeared to be effective in the short term, the child's night waking problem had returned. This parent had Multiple Sclerosis and was confined to a wheelchair.

6.2.5.4 Participant 4

Participant 4 was the mother of an 8-year-old male with PDD NOS, epilepsy, and verbal dyspraxia. The parent indicated that her child displayed settling, night waking, and early morning waking, sleep problems that were lifelong and were rated as moderately severe. The child was considered a restless sleeper who would often wake up multiple times per night and cry out. He was usually difficult to re-settle after such awakenings, and a change of bed (as occurred when the family went on holidays) required Vallergan to help him settle to sleep. Current attempts at treatment included placing a music speaker in his room to help settle him to sleep, having a bath before bed or taking a hot water bottle into bed. These treatments were rated as moderately successful. The use of medication was also rated as being moderately successful. Past attempts at treatment included having his younger sister sleep on a mattress beside him in his room. This was moderately successful in the short term (weeks) but not over the long term. A behavioural intervention program had also been used many years earlier both on its own and in conjunction with sleep medication. On its own the program was rated as moderately successful, while the combination of medication and behavioural intervention was highly successful in the short term (weeks). However, once the mother ceased administering medication the child's sleep problems returned.

6.2.5.5 Participant 5

Participant five was the mother of a 5-year-old male with Down syndrome. The child's mother stated that her child (along with his 3-year-old sister) co-slept with her in the mother's bed every night, however she did not really consider this to be a sleep problem, but more of a habit that now needed to be changed. The mother

considered co-sleeping to be good practice that had been implemented since the child's birth. The mother stated that she now wanted her child to sleep in a separate bed (but in the same room as the parents) due to his age and size. She also stated that due to both her children co-sleeping and taking up all the room in the bed her husband was forced to sleep in another bed in the same bedroom. The mother had recently tried putting the children in their own bed explaining to them why this change was necessary, but the children cried and refused to settle there. The mother also moved the children's bed so that it was next to hers, but this was also met with strong resistance from the children.

6.2.6 Data Analysis

Due to the small number of participants, data were analysed on an individual basis. Descriptive statistics were calculated for all of the parent questionnaires, and for the BEDS and DBC, analysis involved assessing whether or not participants moved out of the clinical range.

To calculate the GAS success as a percentage, the following formula was used where the aim was to increase the target behaviour:

$$\frac{\text{Obtained rate of behaviour} - \text{baseline rate of behaviour}}{\text{target rate (100\% success goal)} - \text{baseline rate of behaviour}}$$

To calculate the GAS percentage success where the aim was to decrease a target behaviour, the following formula was used:

$$\frac{\text{baseline rate of behaviour} - \text{Obtained rate of behaviour}}{\text{baseline rate of behaviour} - \text{target rate (100\% success goal)}}$$

The child and parent sleep diary data were analysed using visual analysis of graphs.

For the children's sleep diary data, the following variables were analysed:

1. Time taken to fall asleep
2. Number of nights where the child co-sleeps
3. Number of night wakings
4. Time spent awake after night waking
5. Total sleep time
6. Overall sleep quality rating

For the parent's sleep diary data, the following variables were analysed:

1. Total sleep time
2. Number of night wakings
3. Overall sleep quality rating

The sleep diary data were averaged weekly and the variables were graphed by plotting the target variable (Y axis) over time (X axis) across the three phases of the study. To allow for visual comparison across participants, the scale of the Y-axis was kept the same in order to represent the same value and equal change. However, the graphs were constructed differently when using visual analysis to examine for individual change on a sleep variable. Each individual graph was displayed on a sheet of A4 paper in landscape view and was not labelled. Visual analysis was used to make the following comparisons: Baseline versus intervention, and baseline versus follow-up. To assess reliability of the visual analysis two independent raters (one not involved with the study) were given an indication of the desired direction of change. They then examined each graph according to a set of modified criteria (Hudson et al., 1995; Thackeray & Richdale, 2002; Weiskop et al., 2005) on the following scale:

1. Substantial change – Data shows a significant increase (to very high or maximum levels of occurrence) or a significant decrease (to very low or almost zero levels of occurrence) in the variable.
2. Moderate change – Data shows a clear increase or decrease in the variable, but the change is not sufficient to be considered substantial.
3. No Change – No change in the data from baseline levels is apparent.

Percentage agreement between the independent raters was calculated, and if the raters disagreed on a rating they conferred and came to an agreement.

6.3 Results

6.3.1 Participant Attrition

Results are not described for participant 1 and participant 5 as they did not complete the intervention program. Participant number 1 attended session 1, missed session 2 and then chose not to return stating that she could not afford the extensive travel time involved. Participant 5 attended session 1, missed session 2 and session 3, attended session 4 and then chose not to complete the program without stating a clear reason. The remaining three participants completed the Signposts program and attended all sessions. The child sleep data will be presented first, followed by the daytime behaviour data, the parent data, and program evaluation data.

6.3.2 Child Sleep Results

6.3.2.1 BEDS Data

Individual scores on the BEDS are shown in Table 6.3. Based on data from a sample of TD children (Schreck et al., 2003) individual factor scores for each child were calculated using a three-point scale (Thackeray & Richdale, 2002):

1. Normal (within one standard deviation of the control mean)
2. Above average (over one standard deviation above the control mean)
3. In the clinical range (over two standard deviations above the control mean)

For Child 2 high scores were reported for the DA factor at baseline. The DA factor score improved at post-intervention, and while the change was not maintained at follow-up this score was still within the normal range. The Parasomnias score showed a slight increase at follow-up.

Improvements from the baseline phase to the post-intervention phase occurred for Child 3 on the BEDS total score and all of the BEDS factors. All improvements were maintained at follow-up. The Dyssomnias and Parsomnias scores had improved greatly by post-intervention. While scores did improve on the ESD and the AP factors, Child 3 still rated higher than the average on these factors at follow-up.

Child 4 also improved from baseline to post-intervention on the BEDS total score and all of the BEDS factors, and improvements on most of the factors were maintained. The ESD factor improved from the clinical range at baseline to be within the normal range at post-intervention and follow-up. The SE factor was within the clinical range at baseline, and decreased to be above average at post-intervention and follow-up. Scores decreased on the DA factor, however, this was still within the clinical range at post-intervention and follow-up. While for the Parasomnias factor and the AP factor improvements at post-intervention were not maintained.

Table 6.3. Individual BEDS Scores at each Phase Compared to Control Scores

Participant	Total	Dyssomnias	Parasomnias	ESD	SE	DA	AP
Child 2							
Baseline	60	45	16	2	2	7	0
Intervention	61	50	13	1	2	4	0
Follow-up	62	46	22	1	3	7	1
Child 3							
Baseline	119	78	45	14 ^c	4	5	3 ^b
Intervention	67	41	32	9 ^c	1	3	2 ^b
Follow-up	58	43	16	7 ^b	1	1	2 ^b
Child 4							
Baseline	148	106	46	10 ^c	14 ^c	13 ^c	3 ^b
Intervention	110	88	24	3	9 ^b	11 ^c	0
Follow-up	122	91	36	5	12 ^b	11 ^c	2 ^b

^b Denotes above average scores, falling outside one standard deviation of controls.

^c Denotes clinical scores, falling outside two standard deviations of controls

6.3.2.2 GAS for Target Sleep Behaviour

Each parent chose a sleep problem behaviour to focus on during intervention, and from the baseline rate of behaviour set a goal that became the 100% success criterion. Table 6.4 shows the sleep problem behaviours for each child, and the success levels obtained at post-intervention and follow-up.

At the end of intervention two parents reported improvement on their child's sleep problem behaviour achieving greater than 70% success. These improvements were maintained at follow-up with two goals achieving 100% success. However, the parent of Child 2 only recorded the behaviour for 2 out of 14 nights. Child 3 showed the greatest improvement in the sleep problem behaviour reaching 96% success at post-intervention, and 100% success at follow-up. While for Child 4 a slight decrease in time taken to settle was noted. The level of success for Child 4 was less than 40% and was not considered to be clinically significant.

6.3.2.3 Child Sleep Diaries

Parents of child 2 and child 4 did not fully complete the sleep diaries. The parent of child 2 only completed the sleep diaries for four days in the first week of follow-up while the diary was not completed in the second week. The parent of child 4 did not complete the diaries for weeks 2 and 5 of intervention. In total, 27 graphs were rated and 54 comparisons between phases were made. The two raters agreed on 43 (79.6%) of the comparisons. Table 6.6 shows the visual analysis ratings for the child sleep variables.

Table 6.4. Participant GAS Success for Sleep Problem Behaviour

Participant	Description of Sleep Problem Behaviour	Average Baseline Rate	100% Goal	Average Post- intervention Rate (% Success)	Average Follow-up Rate (% Success)
Child 2	Taking a long time to settle, plays/restless	35 minutes	20 minutes	24 minutes (73%)	15 minutes (100%) ^a
Child 3	Waking up and crying/calling out	33 times	7 times	8 (96%)	3 (100%)
Child 4	Taking a long time to settle, out of bed, light on	51 minutes	20 minutes	39 minutes (39%)	39 minutes (39%)

^a Parent only recorded target behaviour for four nights over the two week follow-up period.

Table 6.5 indicates that two of the children showed a decrease in the amount of time taken to fall asleep at intervention compared to baseline. This improvement was maintained at follow-up. Figure 6.1 shows an immediate decrease in time taken to fall asleep for child 2 with the onset of intervention, while child 4 showed great variability in sleep onset across all three phases of the study.

Table 6.5. Ratings for Sleep Variables with Baseline Compared to end of Intervention and Follow-up

Sleep Variable	No Change		Mod. Improv.		Subs. Improv.	
	Inter.	FU	Inter.	FU	Inter.	FU
Time take to fall asleep	1	1	2	2	0	0
Co-sleeping*	3	3	0	0	0	0
Night waking	2	1	1	1	0	1
Time spent awake during each night waking episode	2	1	0	1	1	1
Total sleep time	2	2	1	1	0	0
Sleep quality	2	1	1	2	0	0

* No change was expected for 2 children as it was not a problem at baseline.

Figure 6.2 shows that for two of the children no change was expected in co-sleeping as this was not an issue at baseline. For child 4 the frequency of co-sleeping displayed an erratic pattern during the baseline phase. Early in the baseline phase child 4 was co-sleeping between 1-4 times per week. However, during the last two weeks of the baseline period co-sleeping did not occur at all.

The frequency of night waking is depicted in Figure 6.3. One child showed improvement at post-intervention, and two children showed improvement at follow-up. In one case there was a decreasing trend in night waking at baseline. Figure 6.4 also shows the average amount of time each child spent awake during each night

waking episode. For two children there was a decrease in night waking time at follow-up, while one child showed an increase during the intervention phase that had returned to baseline levels at follow-up.

Parental reports of child sleep duration are shown in Figure 6.5. One child displayed steady improvement in total sleep time at the intervention phase, and this improvement was maintained at follow-up. One child showed no improvement in sleep time, while for another child there was a decrease in total sleep time from baseline to post-intervention and follow-up.

Figure 6.6 shows parent ratings of child sleep quality. One child displayed an increase in sleep quality at during the intervention phase and at follow-up. One child showed an initial decrease in sleep quality with intervention onset, but by the end of intervention and follow-up sleep quality ratings were similar to the high ratings that were reported at baseline. Another child displayed irregular scores on sleep quality at baseline. Ratings during the intervention and follow-up phase showed no improvement from baseline scores.

6.3.2.4 Subjective Ratings of Sleep Change

Subjective ratings of change in sleep behaviour were examined from parental responses to specific questions in the BEDS, the DBC, and the PHS. The final question of the BEDS asked parents to answer whether they thought their child had a sleep problem. At the end of intervention two parents reported that their child no longer had a sleep problem, while the parent of child 4 still thought their child had a sleep problem. At follow-up all three parents no longer considered their child to have a sleep problem.

Item 67 of the DBC referred to the child having disrupted sleep. At baseline two parents gave this item a rating of 1 (somewhat or sometimes true). At follow-up they had changed their rating to 0 (not true). The parent of child 4 rated this item 2 (very true or often true) at baseline and 1 at follow-up. Item 69 referred to the child sleeping too much. The parent of child 3 rated this item 2 at baseline, and 0 at follow-up, while the other parents rated this 0 at baseline and follow-up. Item 30 referred to the child having nightmares, night terrors, or walking in their sleep. The parent of child 3 rated this 0 at baseline, and 1 at follow-up, while the other two parents rated this 0 at both baseline and follow-up.

Item 20 and 21 of the PHS referred to having problems getting the child to bed or sleep, and problems with the child waking up often. For the parent of Child 2 both hassles reduced from the moderate level hassle at baseline to a minor level hassle at post-intervention and follow-up. While for the parent of Child 3 waking decreased from a moderate hassle to become no hassle at post-intervention and follow-up. Getting the child to bed or sleep was listed as no hassle from baseline and remained as such throughout the Study. For the parent of Child 4 both items were rated as major hassles at baseline and showed no improvement at post-intervention. At follow-up the child waking decreased slightly in hassle level, but was still rated as a severe hassle, while getting the child to bed or sleep remained a major hassle.

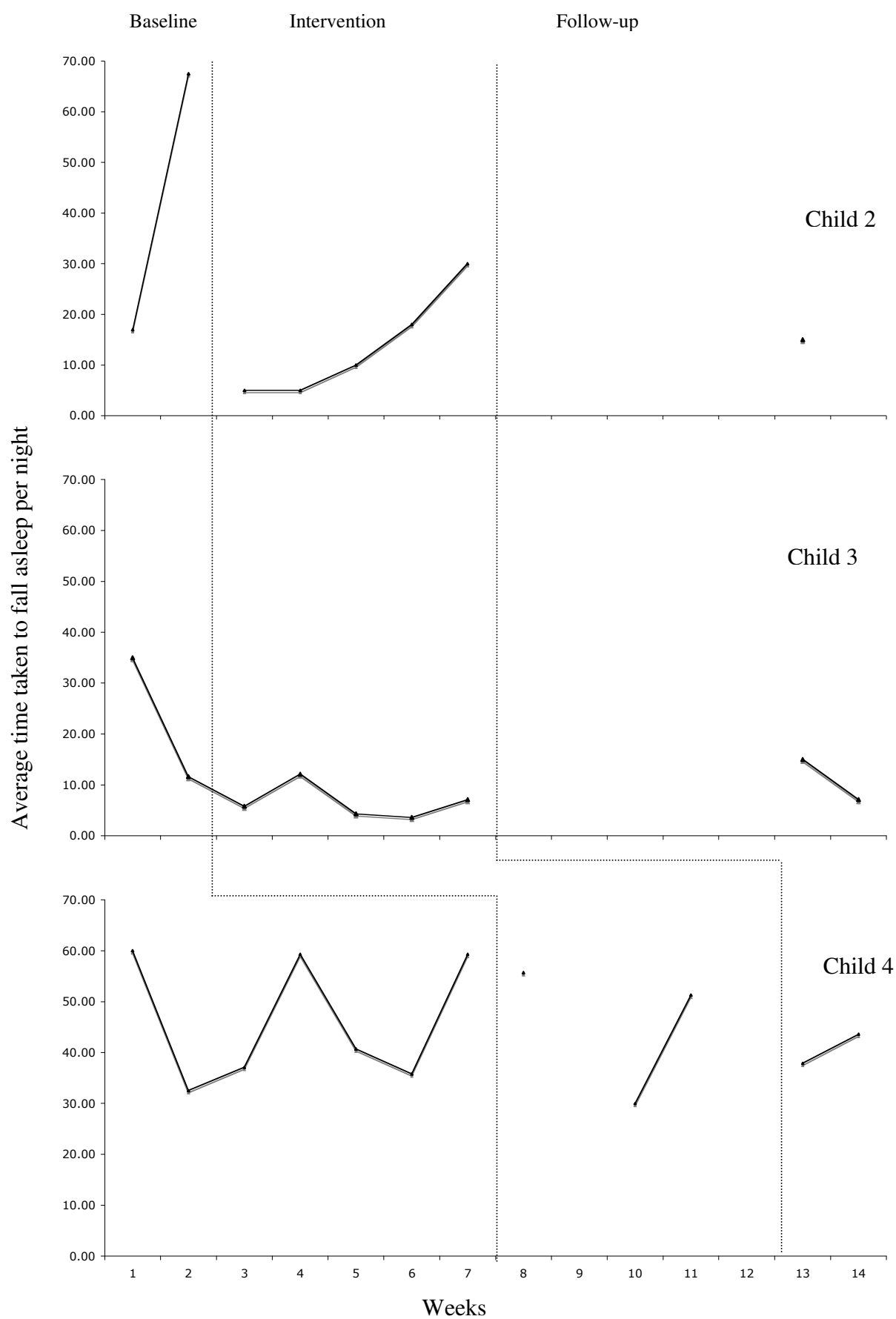


Figure 6.1. The amount of time taken to fall asleep for each child, during baseline, intervention, and follow-up.

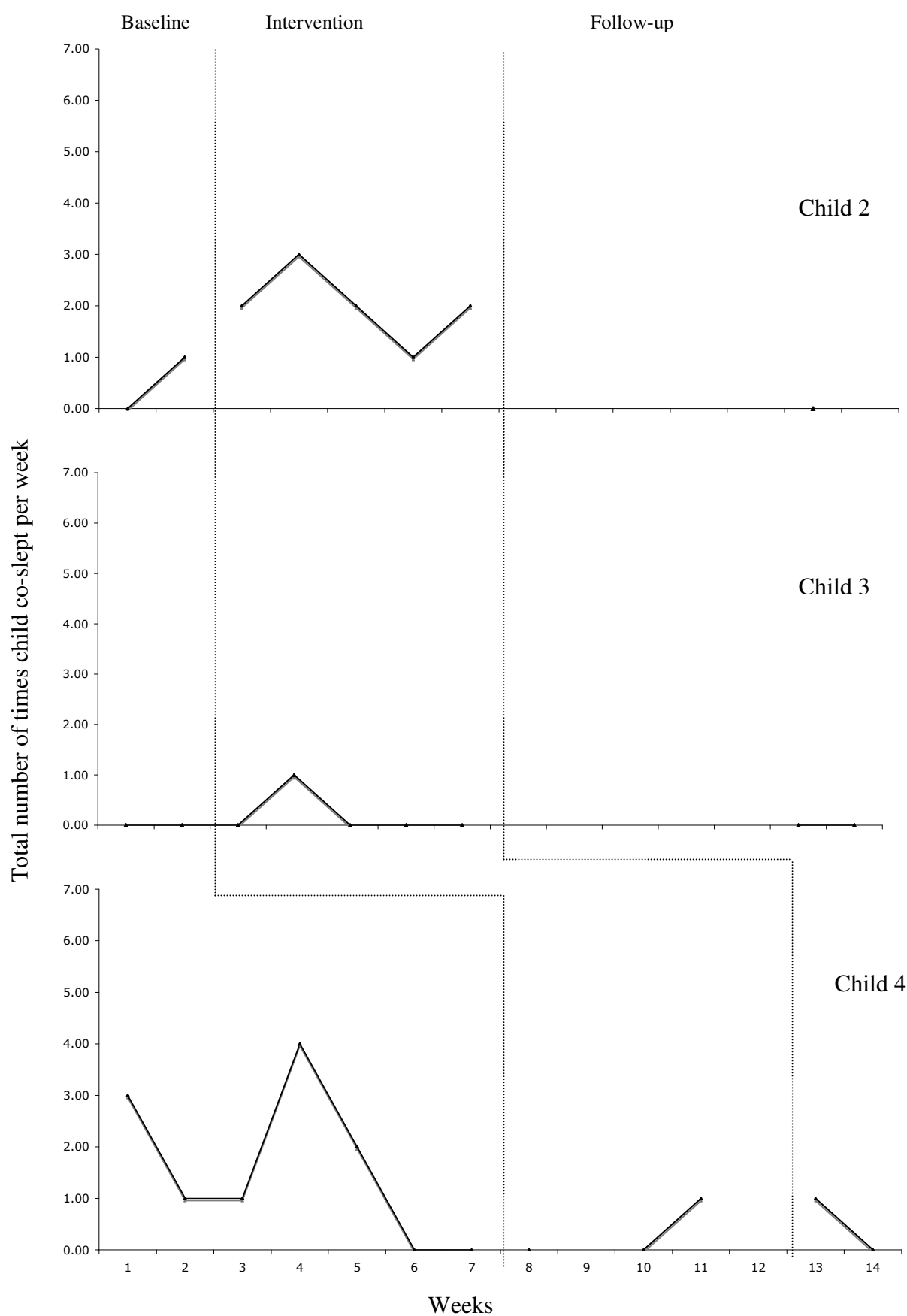


Figure 6.2 . The number of times each child co-slept per week, during baseline, intervention, and follow-up.

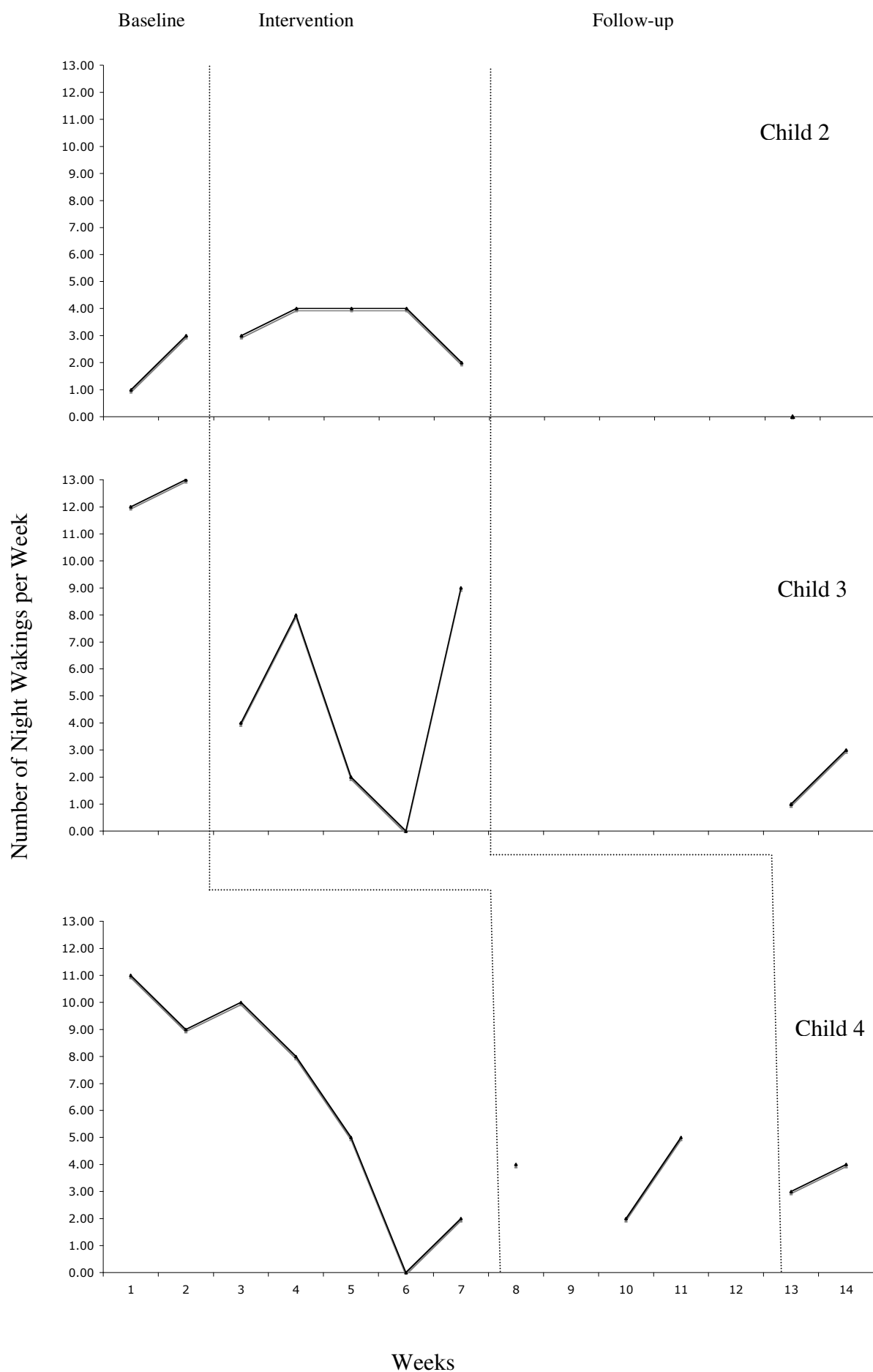


Figure 6.3. Number of times each child woke at night, during baseline, intervention and follow-up.

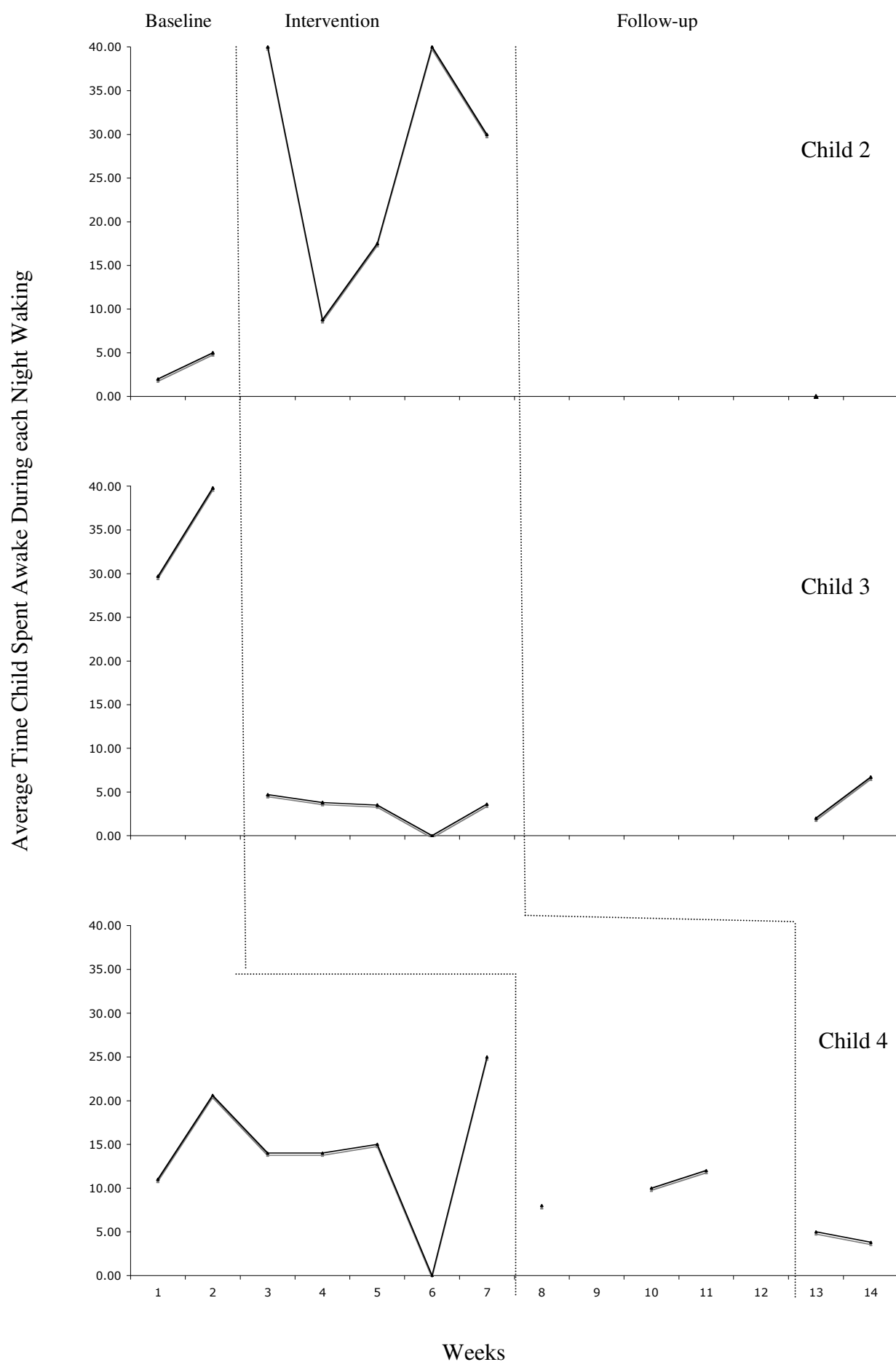


Figure 6.4. The average time each child spent awake with each night waking episode, during baseline, intervention and follow-up.

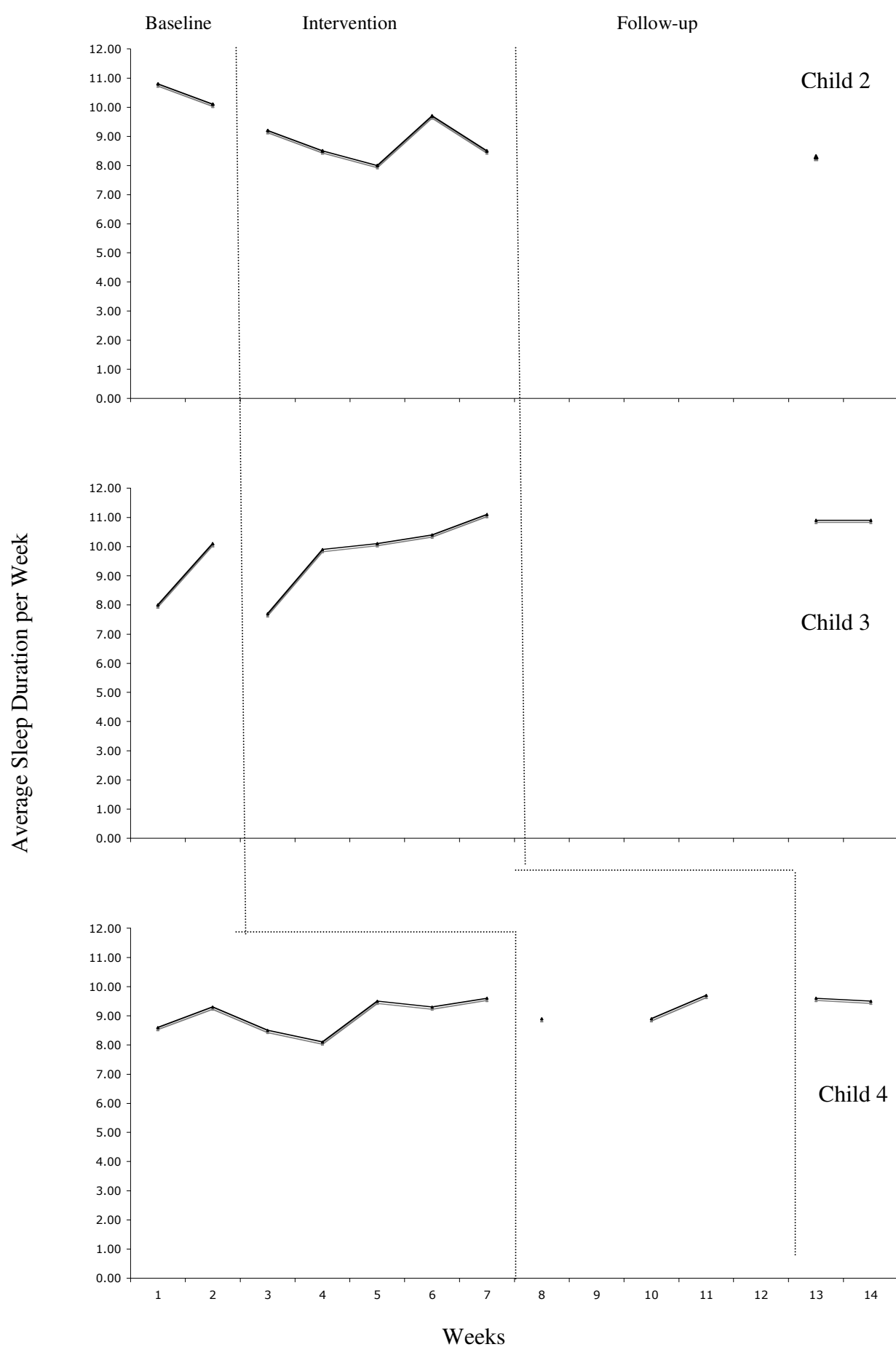


Figure 6.5. The average weekly sleep duration of each child during baseline, intervention and follow-up.

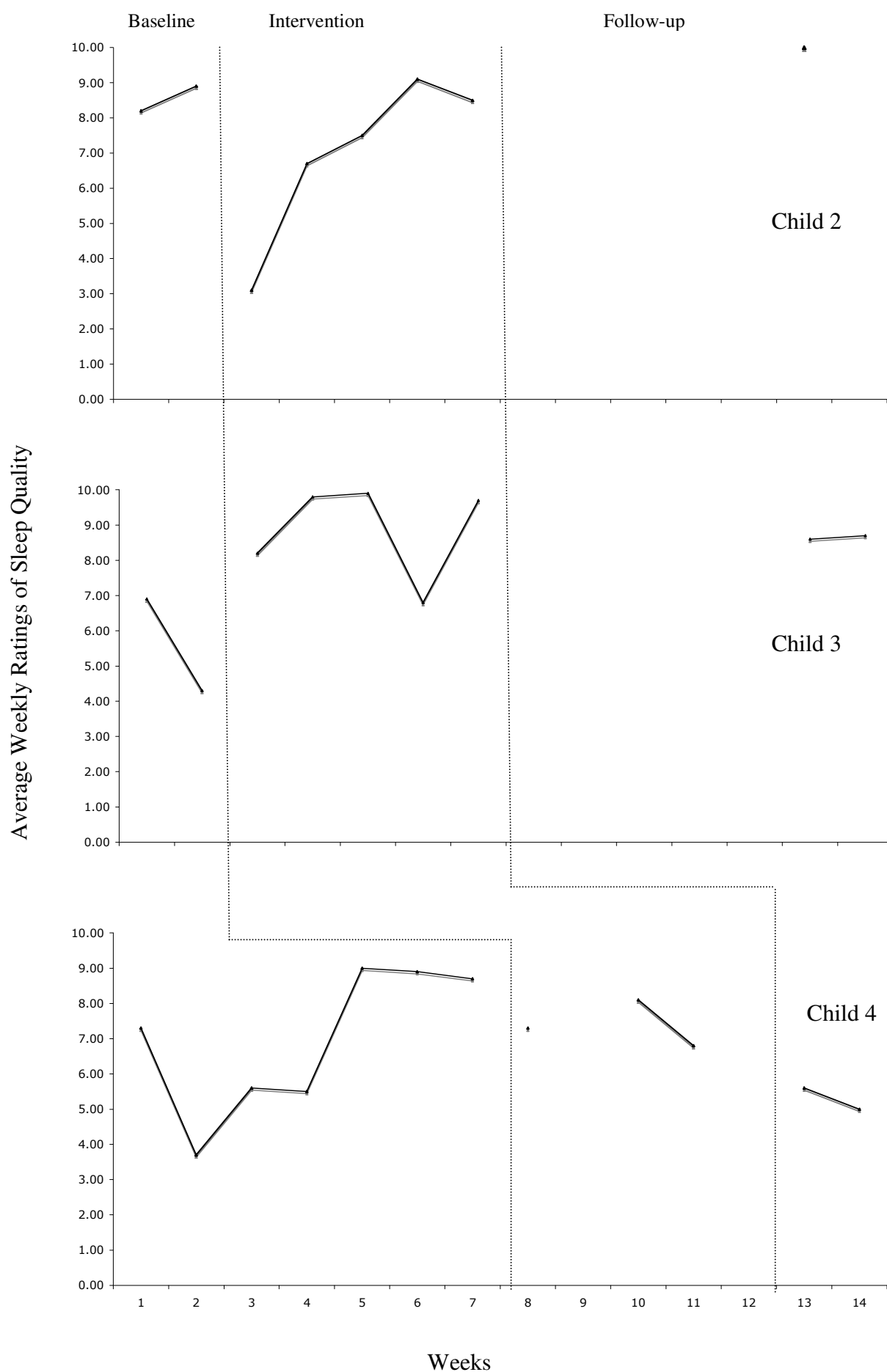


Figure 6.6. Average weekly ratings of sleep quality during baseline, intervention and follow-up

6.3.3 Results for Child Daytime Behaviour

6.3.3.1 DBC Results

Individual raw scores and percentile rank scores are shown in Table 6.6. At baseline all three children had very high scores on all of the subscales that were within the clinical range. Two children displayed a clear decrease in the total score at follow-up, however, they did not move out of the clinical range. Child 3 decreased on all scales and moved out of the clinical range on the disruptive/antisocial scale as well as the anxiety scale. Child 4 also decreased on all scales and moved out of the clinical range on the communication disturbance subscale. Scores for Child 2 remained stable.

6.3.3.2 GAS for Target Daytime Behaviour

Each parent chose to focus compliance to parental requests as the daytime behaviour that was to be increased during intervention, and from the baseline rate of behaviour set a goal that became the 100% success criterion. Table 6.7 shows the success levels obtained at post-intervention and follow-up.

At the end of intervention all three parents reported improvement on compliance, with child 2 reaching 100% success. This improvement was maintained at follow-up, although the parent only completed four days of behaviour recordings. Child 3 showed slight improvement in compliance, however, the baseline level of compliance was higher than the parent expected. Child 4 showed moderate improvement in compliance at post-intervention, but at follow-up this had returned to baseline level.

Table 6.6. Individual DBC Scores and Percentile Rank at Baseline and Follow-up

Participant		Disruptive		Communication					
		Total Score	/Antisocial	Self-Absorbed	Disturbance	Anxiety	Social Relating		
		Raw (% Rank)	Raw (% Rank)	Raw (% Rank)	Raw (% Rank)	Raw (% Rank)	Raw (% Rank)	Raw (% Rank)	Raw (% Rank)
Child	2								
	Baseline	78 (92 nd)	22 (80 th)	32 (94 th)	13 (94 th)	6 (80 th)	4 (58 th)		
	Follow-up	76 (92 nd)	25 (86 th)	27 (90 th)	11 (90 th)	8 (90 th)	5 (70 th)		
Child	3								
	Baseline	81 (92 nd)	15 (64 th)	38 (98 th)	8 (78 th)	8 (90 th)	9 (90 th)		
	Follow-up	60 (78 th)	9 (42 nd) ^a	34 (96 th)	6 (66 th)	3 (48 th) ^a	7 (82 nd)		
Child	4								
	Baseline	90 (96 th)	32 (96 th)	26 (88 th)	12 (92 nd)	9 (94 th)	7 (82 nd)		
	Follow-up	53 (70 th)	18 (74 th)	19 (76 th)	5 (56 th) ^a	5 (72 nd)	4 (58 th)		

^aDenotes that the score is no longer in the clinical range

Table 6.7. Participant GAS Success for Compliance to Parent Request

Participant	Average Baseline Rate	100% Goal	Average Post-intervention Rate (% GAS Success)	Average Follow-up Rate (% GAS Success)
Child 2	53 %	70 %	98 % (100%)	95 % (100%) ^a
Child 3	65 %	80 %	69 % (27%)	71 % (40%)
Child 4	46 %	80 %	60 % (41 %)	43 % (0%)

^a Parent only recorded target behaviour for four nights over the two week follow-up period

6.3.4 Results for Parent Factors

6.3.4.1 Results from Parent Questionnaires

Individual scores on each measure are represented in Table 6.8. Group means on perceived control over difficult sleep behaviour showed an increase at post-intervention, with a further increase obtained at follow-up. An examination of individual scores revealed an increase in perceived control for the mothers of child 3 and child 4 at post-intervention with further gains made at follow-up. For child 2 an improvement in perceived control was obtained at follow-up.

The group mean on perceived control over daytime behaviour decreased slightly at post-intervention, but was higher than the baseline score at follow-up. Individual scores show that the mother of child 3 reported an increase in perceived control at post-intervention and follow-up. For child 4 perceived control had increased at follow-up. While for child 2 perceived control decreased from the baseline score.

Table 6.8. Individual Scores for Parent Measures at each Phase

	Perceived Control		Parent Hassles Scale				Parenting Sense of Competence		
	Sleep	Behaviour	Total	Child Behaviour	Parent Needs	Education /Development	Total	Satisfaction	Efficacy
Child 2									
Baseline	2.9	7.8	112	80	27	5	66	37	29
Intervention	3.0	2.1	109	72	30	7	65	39	26
Follow-up	5.5	4.5	147	87	47	13	_ ^a	_ ^a	_ ^a
Child 3									
Baseline	4.8	4.4	131	57	63	11	43	26	17
Intervention	7.2	8.2	111	59	48	4	67	36	31
Follow-up	9.0	9.2	75	41	29	5	67	35	32
Child 4									
Baseline	2.5	5.5	185	104	65	16	55	33	22
Intervention	5.5	5.3	165	87	62	16	65	33	32
Follow-up	6.9	7.6	161	98	49	14	65	35	30

^a The parent of Child 2 did not complete this measure at follow-up.

A decrease in the group scores occurred on all scales of the PHS at post-intervention, with the parent needs scale showing further improvement at follow-up. An examination of the individual scores showed that two mothers reported a decrease on the parent needs scale while one parent displayed an increase on this scale. Scores on the child behaviour hassle scale decreased for two parents at post-intervention but improvements were not maintained, while one parent showed a decrease at follow-up. Scores on the education/development hassle scale decreased for one parent, increased for one parent, and showed no change for one parent.

The mother of child 2 did not complete the PSOC at follow-up, hence, group scores at follow-up are not reported. Group scores increased on all aspects of the PSOC at post-intervention. Individual scores on the PSOC show that efficacy increased at post-intervention with improvements maintained at follow-up. An increase for the mother of child 3 was also obtained for the satisfaction scale.

6.3.4.2 Results from Parent Sleep Diaries

Parents of child 2 and child 4 did not fully complete their sleep diaries. The parent of child 2 only completed the sleep diaries for four days in the first week of follow-up and the diary was not completed in the second week. The parent of child 4 did not complete the diaries for weeks 2 and 5 of intervention. Table 6.9 shows the visual analysis ratings for the parent sleep variables.

Parent of child 3 had an increase in total sleep time at post-intervention, however, this increase was not maintained at follow-up. Figure 6.7 illustrates the sleep duration graphs of each parent. The parent of child 2 had a decrease in total

sleep time during the intervention phase compared to her total sleep at baseline while the parent of child 4 did not report a change in total sleep time.

Table 6.9. Ratings for Parent Sleep Variables with Baseline Compared to end of Intervention and Follow-up

Sleep Variable	No Change		Mod. Improv.		Subs. Improv.	
	Inter.	FU	Inter.	FU	Inter.	FU
Total parent sleep time	2	3	1	0	0	0
Number of parent night wakings	1	1	2	0	0	2
Parent sleep quality	1	2	2	1	0	0

Graphs of parent night wakings are represented in Figure 6.8. Two parents had a decrease in the number of times they woke during the night, and this improvement was maintained at follow-up. The parent of child 2 showed an immediate decrease in night waking with the onset of intervention, while the parent of child 3 showed a steady decline in night waking. The parent of child 4 displayed elevated night waking frequency in the first two weeks of baseline, with the frequency remaining stable thereafter.

Figure 6.9 illustrates average weekly ratings of parent sleep quality. Baseline scores for all three parents were in the moderate range, with two parents showing an increase during the intervention phase. The parent of child 2 was reporting high sleep quality from the onset of intervention, and this remained high through to follow-up. For the parent of child 3 sleep quality increased during intervention until the final week, and follow-up ratings were similar to baseline levels. For the parent of child 4 ratings fluctuated early during baseline and were high for the last three

weeks of the baseline phase. Ratings during intervention and at follow-up showed no improvement in sleep quality.

6.3.4.3 Parent Evaluation of Intervention Program

Parent satisfaction ratings in relation to the Signposts program were high ($M=38$, $SD=2.6$) at the end of intervention. All parents stated that the program had assisted them in managing their child's sleep and general daytime behaviour. One parent stated that they would have liked the program to run longer to avoid cramming the material into six sessions. One parent stated that the location of the program was a travel burden for her, and that she would have liked the program to have more participants, creating more of a group atmosphere. One parent reported that program had helped her immensely on a personal level as well as assisting with her child's sleep and daytime behaviour.

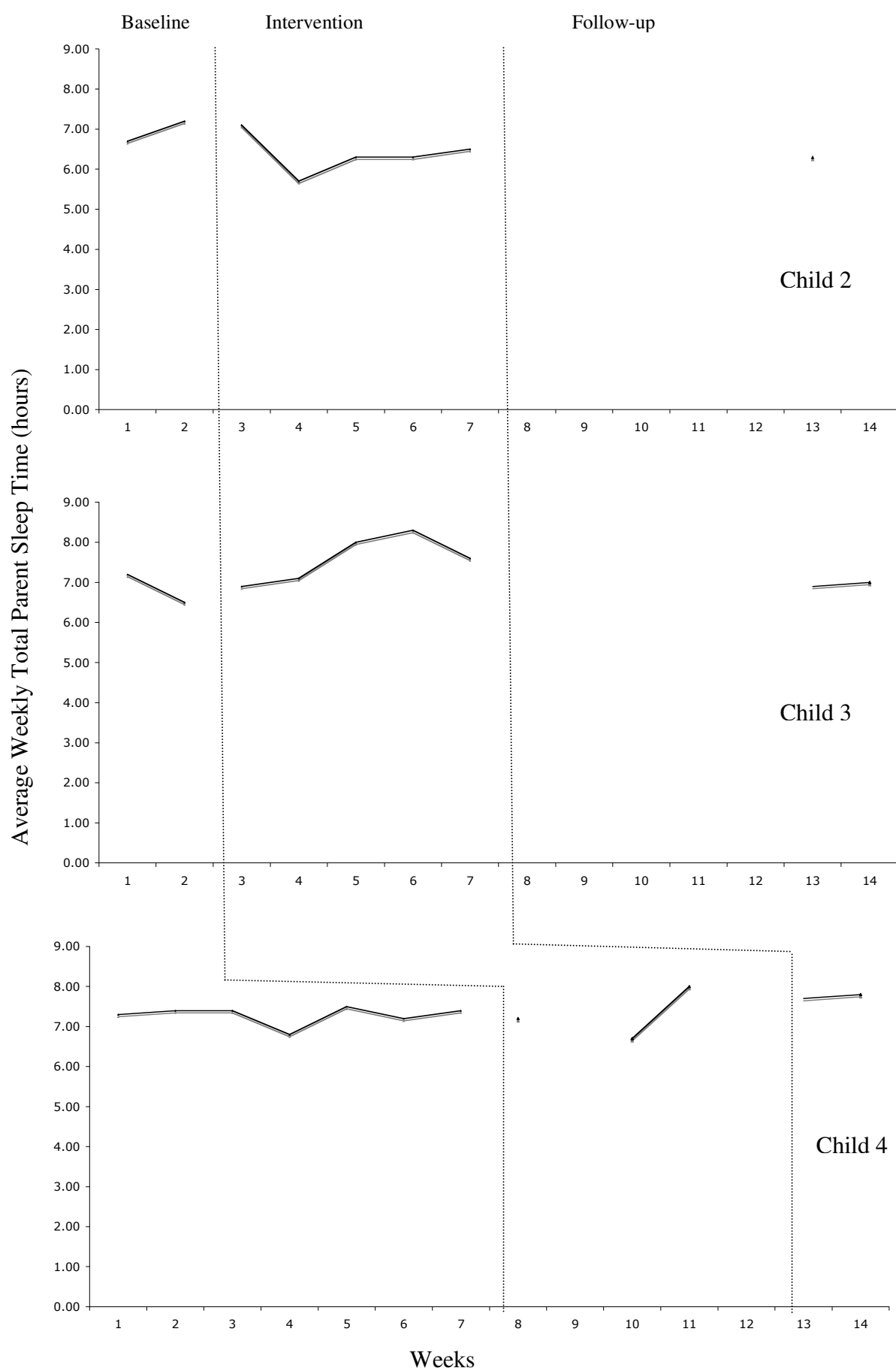


Figure 6.7. The average total sleep duration for each parent during baseline, intervention and follow-up.

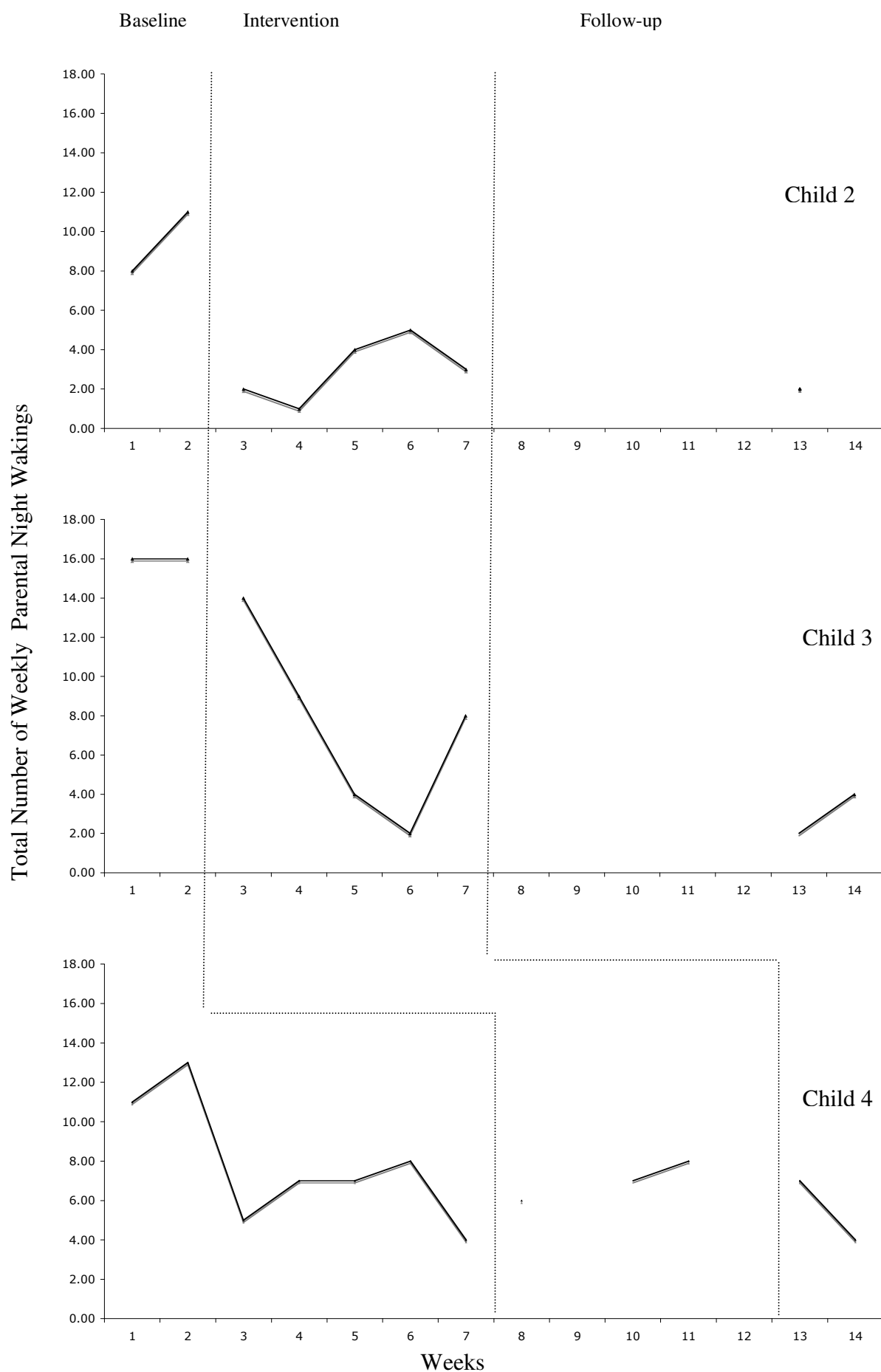


Figure 6.8. Number of times each parent woke at night during baseline, intervention and follow-up.

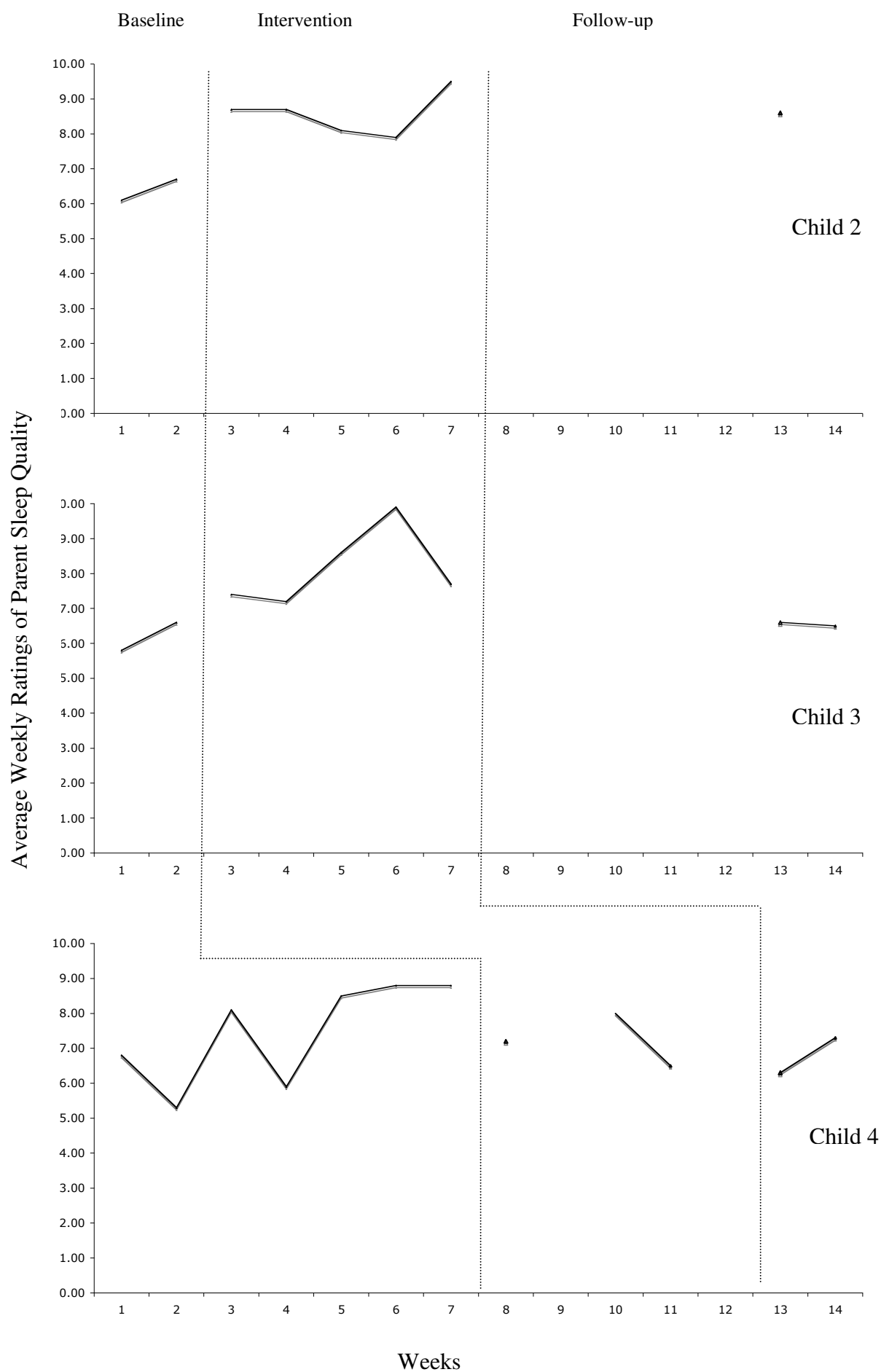


Figure 6.9. Weekly average ratings of parental sleep quality during baseline, intervention and follow-up.

6.4 Discussion

The aim of this study was to determine whether a general behaviour intervention program for parents of children with an ID using sleep as a training exemplar is effective in treating night waking, night settling, and co-sleeping problems. Further aims of this study were to determine if the intervention program also led to an improvement in the daytime behaviour of the child and an improvement in parent factors as well.

It was hypothesised that the intervention program would lead to a reduction in sleep problems. This hypothesis was partially supported. At the end of the intervention two parents no longer considered their child to have a sleep problem, and by follow-up all three parents reported that they did not believe their child had a sleep problem. Furthermore, all parents reported improvement in their child's target sleep behaviour. Improvements for two of the children were also seen on the BEDS and through the use of sleep diaries.

It was also hypothesised that the intervention program would lead to an improvement in the child's daytime behaviour. This hypothesis was partially supported. For two of the children there was a reduction in the total behaviour problem score of the DBC at follow-up, and modest improvement was noted on each of the subscale scores with some scores moving out of the clinical range. Both parents reported improvement in child compliance at post-intervention, however, for one child the improvement was not maintained at follow-up. While for the other child an improvement in behaviour on the DBC was not obtained, improvement in the targeted behaviour of compliance to parental requests was achieved.

Finally, it was hypothesised that the intervention program would lead to an increase in parental perceived control over the child's sleep and daytime behaviour,

greater confidence in parenting ability, and a decrease in parent hassles. This hypothesis was partially supported. Two parents reported an increase in perceived control over sleep and daytime behaviour, a decrease in parent hassles, and an increase in parent efficacy.

6.4.1 Child Sleep Outcomes

Two children with lifelong sleep problems, and one child with a five-year history of sleep problems, showed an improvement in their sleep behaviour. Two of the parents no longer considered their child to have a sleep problem at the completion of the intervention program, and at six-month follow-up all three parents believed that their child no longer had a sleep problem. Improvement on the BEDS was demonstrated with two children moving out of the clinical range on some subscales. The third child did not improve on the BEDS, however scores on the subscales were within the normal range throughout the three phases of the study. All of the children showed a decrease in the targeted sleep behaviour with two parents achieving 100% success on their GAS. Despite these findings, the sleep diary results showed that only one child displayed concomitant improvement in their sleep, with an increase in total sleep time and sleep quality ratings reported. For the other two children sleep diary results did not show clear improvement in the child's sleep. This may partly be explained by the fact that these parents were not as consistent in their completion of the diaries. Furthermore, a lack of improvement in the night waking, total sleep time, and sleep quality in the diaries were most likely due to the fact that both children were not toilet trained. Parent reports on the sleep diaries indicated that the majority of night waking episodes for each child were the result of the child waking to go to the toilet or having wet the bed.

Overall the results suggest that two of the three children demonstrated improvement in their sleep behaviour, and that specific chronic sleep problems had been resolved to the parents' satisfaction. These improvements were maintained at six-month follow-up. For one child a slight improvement in sleep behaviour was obtained, however, this child was still taking a considerable amount of time (average 40 mins per night) to settle to sleep.

6.4.2 Child Daytime Behaviour Outcomes

At baseline all three children had a very high level of difficult behaviour, with each child ranked above the 90th percentile on the DBC. Two children displayed improvement in their daytime behaviour at follow-up, showing a decrease on all scales, and moving outside the clinical range on some scales. The other measure of child behaviour that parents specifically chose to target was compliance to requests. By the end of intervention each parent had recorded an increase in the child's level of compliance to parental requests. This increase was maintained at follow-up for two of the children.

Bramble (1997) has reported significant improvements in child daytime behaviour after treating the sleep problems of children with an ID. To date, other sleep intervention studies have not reported associated improvements in daytime behaviour after successful sleep problem treatment (Thackeray & Richdale, 2002; Weiskop, 2001; Wiggs & Stores, 1999). In this study, a general behaviour intervention produced little to moderate improvement for child daytime behaviour.

6.4.3 Parent Outcomes

Bramble (1997), and Wiggs and Stores (2001a) have reported improvements in parental stress, sleep quality, and perceived control with the successful treatment of sleep problems in children with an ID. In this study parent perceived control over the child's sleep problem increased for two parents at post-intervention, and for all three parents at follow-up. Furthermore, one parent showed a strong decrease in the intensity of parent hassles, specifically regarding the parent needs scale. An increase was also noted for two parents in relation to parenting efficacy. Two parents reported a decrease in night waking, and slight increases in sleep quality, however, an increase in total sleep time was not reported.

6.4.4 Comparison of Results Across Participants

Of the three parents involved in Study 3, the parent of Child 3 reported strong improvement across multiple sleep variables and moderate improvement in the child's daytime behaviour. Additionally, improvements in measures of perceived control over the child's sleep behaviour and daytime behaviour, confidence in parenting ability, and hassle intensity were reported for this parent as well. For this parent the intervention was a success. This would suggest that a parent-training program, with sleep used as a training exemplar, can be effective in resolving sleep problems as well as general behaviour problems for children with an ID. However, for two of the parents the intervention was not as effective. While the child's specific sleep problem improved, little to no improvement was noted on other sleep variables. Furthermore, the daytime behaviour of the children, and the level of parent hassles showed minimal or no improvement. Both parents reported an increased perceived

control over the child's sleep behaviour, and one parent reported a higher perceived control over the child's daytime behaviour and higher parental efficacy.

One possible reason to explain why the intervention was effective for only one of the three parents relates to the level of commitment shown by the parents towards the program. In order for the intervention to be effective parents were required to implement the plan that they developed during the intervention sessions. Perhaps the parent of Child 3 was more prepared to use and persist with the behavioural strategies that were taught in the program. This was evidenced by the fact that the parent of Child 3 completed her sleep diary data on a regular basis compared to the other two parents who provided less complete sleep diary data. It is worth noting that the parent of Child 2 reported a high score on parenting efficacy at baseline, indicating a high level of perceived parental competency. This parent was also satisfied within the parenting role. Therefore, this parent may not have been as committed to the program.

Another possible reason could relate to child specific factors such as the severity of epilepsy. All three children had epilepsy, however, the specific type, level, and influence that this had on the child was not discerned. Alternatively, there may have been some other attributable factor to explain the comparative lack of effectiveness of the intervention program for two parents.

6.4.5 Study Limitations

The small number of participants in Study 3 was a clear limitation as this cannot be considered a representative sample and also prevented statistical analysis from being conducted on the sleep, behaviour, and parental measures that were used to test the effectiveness of the intervention program.

This small sample size was due in part to a lack of willingness from parents to seek help for their child's sleep problem. This finding has been reported in previous studies (Bartlett et al., 1985; Didden et al., 2002; Robinson & Richdale, 2004; Wiggs & Stores, 1996b) and seems to have occurred here as well. Of the 20 parents who reported their child to have a sleep problem in Study 2, 15 said that they were interested in participating in Study 3, but only five parents started the program and just three parents completed the intervention program. Therefore, five parents refused an offer of treatment, while 12 initially agreed to participate in the program and then changed their mind. Reasons given for not undertaking the intervention program included the travel time involved, and not being able to commit to the program because it ran for several weeks. Parental beliefs that the child's sleep problem is related to other causes, or that the sleep problem is permanent and cannot be treated, or that the sleep problem is due to a medical condition or a direct result of the child's disability are all possible reasons why parents do not seek treatment (Bramble, 1996; Robinson & Richdale, 2004; Stores, 2001a).

Another limitation of Study 3 was that the three of the sessions for the intervention program were delivered weekly instead of fortnightly as is recommended. Thus, parents did not have as much time between sessions to use the strategies that had been taught in the previous session. Having fortnightly sessions could have also provided more stable diary recordings from the parents. Unfortunately, due to time constraints, fortnightly sessions were not practical.

Further limitations of Study 3 related to the measures used in recording the child's sleep and behaviour. While sleep diaries are an acceptable form of obtaining sleep data, sleep actigraphy could have yielded some interesting information regarding sleep changes for these children. The parents in Study 3 were asked to

have their children wear Acti-watches but they refused stating that they did not think their children would wear the watch. Thackeray and Richdale (2002) reported that two of three children refused to wear an Acti-watch at follow-up. Bramble (2000) also reported that monitors are susceptible to damage by children with developmental delays. Observations of the child's daytime and sleep behaviour would have also been useful, as further insight would have been gained regarding use and generalisation of the parenting strategies. Physically observing the child at night in the home setting is not very practical and the use of an infra-red camera would be costly.

A further limitation of the study was that parent compliance to intervention was not recorded, thus, it is not possible to discern the extent to which intervention was implemented and whether or not this may have impacted the child and parent outcomes measured. While homework completion is part of the Signposts program parents were not asked to complete this data as they were completing other data requirements specific to the study that were quite onerous (child and parent sleep diaries on a nightly basis).

6.4.6 Conclusion and Future Directions

Previous studies have shown that behavioural intervention is an effective form of sleep problem treatment, however, inconsistent results have been obtained regarding concomitant improvement in the child's daytime behaviour (Bramble, 1997; Thackeray & Richdale 2002; Weiskop, 2001; Wiggs & Stores, 1999). This was the first study to consider the efficacy of a general parent-training program in order to treat sleep problems of children with an ID. The small number of participants and other limitations of the study need to be taken into consideration

when interpreting these preliminary results. Furthermore, it is difficult to compare findings across studies as participant numbers and participant homogeneity are usually low.

Researching the use of a general parent-training program, with sleep used as an exemplar, in order to resolve night settling, night waking and co-sleeping problems in children with an ID is beneficial for two important reasons. First, both parents and professionals are unlikely to address the child's sleep problem (Bartlett et al., 1985, Didden et al., 2002), therefore the number of children who actually receive sleep intervention is very low. This is further exacerbated by the fact that parents who do seek treatment are often recommended inappropriate or incorrect advice for the sleep problem (Wiggs & Stores, 1996b). Second, studies conducted to date have shown that when parents undertake a specific sleep intervention program, generalisation across behaviours does not necessarily occur (Thackeray & Richdale, 2002; Weiskop, 2001). As the behavioural strategies can be equally applied to sleep problems and daytime behaviour problems, a general parent-training program should assist parents to improve both their child's sleep and daytime behaviour.

While the hypotheses from Study 3 were only partially supported, a trend in the data was found that indicated a parent-training program, with sleep used as an exemplar, could be effective in resolving both sleep and behaviour problems of children with an ID. These results warrant further research on this issue.

CHAPTER 7. GENERAL DISCUSSION

7.1 Summary of Findings

7.1.1 Parent Perceptions of sleep problems in children with an ID

Research indicates that night settling, night waking, early waking, and co-sleeping problems are a common occurrence for children with an ID, with high prevalence rates reported across studies (Didden & Sigafos, 2001; Quine, 2001; Richdale et al., 2000). However, some parents do not consider their child's sleep to be problematic (Bartlett et al., 1985; Wiggs & Stores, 1996a). The aim of Study 1 was to assess parental perceptions of their child's sleep. Parents listed their child's sleep disturbances and then reported whether or not they thought their child had a sleep problem.

While 63% of parents rated their child as displaying some type of disturbing sleep behaviour, only 27% of parents believed their child had a sleep problem. One explanation for this discrepancy may relate to the frequency and intensity of the child's sleep disturbance. Children regarded as having a sleep problem had less sleep, were more likely to exhibit night waking, and were more likely to display two or more sleep disturbances. Hence, for some parents who did not consider their child to have a sleep problem, the child's sleep disturbance was mild compared to children whose parents did perceive a sleep problem. However, this explanation does not account for all the parents who did not consider their child to have a sleep problem despite showing sleep disturbance. A number of parents who did not recognise their child as having a sleep problem rated their child's sleep disturbance as moderate, or reported the presence of two or more sleep disturbances, or reported that their own sleep was disrupted as a direct result of the child's sleep disturbance. This finding

supports the results of previous studies (Bartlett et al., 1985; Wiggs & Stores, 1996a; Didden et al., 2002) that some parents of children with an ID recognise child sleep disturbances but do not consider these disturbances to be problematic.

Thus, the aim of Study 2 was to investigate what differentiated parents who did not consider their child to have a sleep problem compared to those who recognised that a sleep problem exists. The study examined whether or not child and parent factors played a role in relation to parent recognition of a sleep problem in children with an ID. To date, only one study regarding this issue appears to have been conducted: Wiggs and Stores (1998b) found that mothers who failed to recognise their child's sleep problem reported less difficult daytime child behaviour, less stress, and a higher perceived control over the child's sleep behaviour. Perceived control, and locus of control were thought to act as stress buffers for these parents thus increasing their resilience. Furthermore, it was proposed that perceived control might be an important coping strategy and could form a component of sleep intervention.

Locus of control is a stable personality trait that has been studied as a stress moderator (Lefcourt & Davidson-Katz, 1991), however, only Wiggs and Stores (1998b) have considered its role relating to sleep problems in children with an ID. Introversion and neuroticism are two other parent personality factors associated with the stress response (Gallagher, 1990). One study has also found a correlation between maternal introversion and neuroticism with sleep problems in TD children (Gelman et al., 1998). It was suggested that mothers high on neuroticism or introversion would have difficulty implementing behavioural interventions that utilised the principle of extinction, and that alternative interventions would be more suitable for these parents.

Study 2 considered whether or not the stable personality characteristics of locus of control, neuroticism and introversion acted as stress buffers for parents who did not recognise their children's sleep problem. Parents in the USP group scored higher on perceived control over the child's sleep behaviour, and higher on perceived control over the general daytime behaviour of the child. The children in the USP group were also rated as obtaining more sleep per night than RSP children. There was no difference between the USP, RSP and NSP groups on child adaptive or daytime behaviour, parent stress, parenting sense of competence, locus of control, neuroticism and extraversion.

Parent perceived control was higher in the USP group compared to the RSP group. These results support a previous finding that there are differences between parents who consider their child to have a sleep problem and those who do not recognise their child's sleep problem (Wiggs & Stores, 1998b). However, the current finding is different to that obtained by Wiggs and Stores (1998b) in that there was no difference between the sleep groups on parent stress or child daytime behaviour. This indicates that perceived control does not necessarily buffer against stress as has been proposed. Instead, it appears to have a direct effect on parental recognition of a child sleep problem. That is, a parent who thinks that they have control over their child's sleep is less likely to consider their child as having a sleep problem. This concept is consistent with Study 1 results showing that parents readily reported that their child had one or more sleep disturbances, and that in many instances such disturbances also disrupted the parent's sleep. Thus, the notion that the parent is ultimately able to control the child's sleep seems to avert the sleep disturbance from being identified as a problem by the parent. This result could have negative implications for both the parent and the child. Parents who experience high stress

levels and difficult child behaviour, but do not recognise a sleep problem, are unlikely to come to the attention of professionals. As a result, the parent is unlikely to receive/seek any treatment for the child's sleep problem and the problem will remain unresolved.

Furthermore, despite similar ratings of child behaviour problems, USP parents also reported higher levels of perceived control over the child's daytime behaviour compared to RSP parents. Thus, parents in the USP group reported similar levels of sleep and behavioural issues as RSP parents, but rated themselves as having more control over their child's sleep and daytime behaviour. These findings lead one to ask the question what influences parent levels of perceived control over child sleep and daytime behaviour? Some factors could include the type of child disability, parent attitudes and beliefs about the child's disability and associated medical conditions, previous experiences managing sleep and behavioural issues, support received from family and professional services, and parent well-being. As perceived control influences parent recognition of a child sleep problem, further research to identify factors associated with perceived control would be valuable.

Another parent factor that differentiated the RSP group from both the USP group and the NSP group was the amount of time that parents reported that their child slept during the night. Parents in the RSP group reported significantly less sleep for their children. This finding may be interpreted one of two ways. Perhaps the children in the RSP group do have less sleep at night than other children. This indicates that parents who recognise their child's sleep problem may do so because the child displays more severe sleep disturbance than the children in the unrecognised sleep problem group. Alternatively, parent sleep ratings may be influenced by other factors such as perceived control over the sleep behaviour, and

tolerance of the child's sleep disturbance. Parents who do not perceive their child's sleep to be a problem, and who are more tolerant of their child's sleep may overestimate the amount of sleep that the child actually obtains, and vice versa. This issue could be further explored by comparing subjective parent ratings of the child's sleep with objective sleep measures such as actigraphy.

The results obtained in Study 2 differed from those of Wiggs and Stores (1998b) where parents in the unrecognised sleep problem group reported better child daytime behaviour and lower stress. A possible explanation for this dissimilarity may be that the two studies used different measurement instruments to assess sleep problems, behaviour problems, and parent stress levels. In Study 2 the child's sleep was assessed using a questionnaire based on ICSD (1991) criteria for childhood parasomnias and dyssomnias. Whereas Wiggs and Stores (1998b) used specific classification criteria in relation to co-sleeping, night settling, night waking, and early morning waking sleep problems. Furthermore, the stress measure used by Wiggs and Stores (1998b) assessed the physical and emotional aspects of stress while the measure used in Study 2 considered parent experience of daily hassles. A short version of the Parenting Hassles Scale (Gavidia-Payne & Stoneman, 1997) was used in Study 2 compared to the full scale that has been used in a previous sleep study (Richdale et al., 2000). The full scale measures the frequency and intensity of parenting hassles on eleven domains, whereas the short form measured the intensity of hassles on three domains. Using the full scale may have been advantageous as it would have yielded a more complete measure of the different hassles experienced in relation to the child with a disability. However the short version forms part of the Signposts package used in Study 3 and was thus used in Study 2 for consistency.

The different results obtained in Study 2 from those of Wiggs and Stores (1998b) may also be due to participant variation across the two studies on factors such as the type and severity of child disability, associated medical conditions, medication use, and cultural differences.

Study 2 revealed that in relation to the issue of parent recognition of a child sleep problem, from Study 1 to Study 2 twelve parents had changed their mind regarding whether or not their child's sleep was problematic. By Study 2, eleven of these twelve parents/carers no longer thought that their child had a sleep problem and one parent/carer now considered their child to have a sleep problem. This was not reported by Wiggs and Stores (1998b); in the time that elapsed between their studies no parent changed their perception of their child's sleep. Two explanations may account for this difference. Firstly, in the current research, the sleep questionnaires used in Study 1 and Study 2 were different. Study 1 used a short sleep screening questionnaire that contained only four sleep questions and then asked parents to rate whether they thought their child had a sleep problem or not. In Study 2 a more comprehensive sleep questionnaire was employed and considered all types of childhood sleep disorders. Perhaps the difference in sleep questionnaires across Study 1 and Study 2 was responsible for a change in parent perception regarding their child's sleep problem.

Secondly, in the three to five months that elapsed between Study 1 and Study 2 the child's sleep may have improved, thus leading to a change of parent opinion regarding recognition of a child sleep problem. This seems unlikely as sleep problems have a tendency to persist unless treated (Quine, 1991; Richdale et al., 2000). Parent descriptions of the child's sleep suggested that many of the children

still had a sleep problem, but the parent no longer considered it to be a problem. This may indicate that parent recognition of childhood sleep problems can be influenced in the short term by factors other than improvement or amelioration of the problem. As the current research did not examine for such factors one can only speculate what may have led to a change in parent recognition of a child's sleep problem. Perhaps in the time that elapsed between Study 1 and Study 2 these parents increased their perceived control over the child's sleep. Alternatively, these parents may have become more concerned about other, more prevalent issues (such as child illness, behavioural issues), and the child's sleep was no longer a major concern.

7.1.2 Treatment of Sleep Problems in Children with an ID

The treatment of night settling, night waking, early waking, and co-sleeping problems in children with an ID is often possible with behavioural intervention, however, parents often do not seek treatment for the problem (Didden et al., 2002; Robinson & Richdale, 2004; Wiggs & Stores, 1996b). Thus, an aim of Study 1 was to examine the proportion of parents who had sought treatment for their child's sleep problem. A higher than expected proportion was obtained with 76.2% of parents reporting that they had sought treatment for their child's sleep problem. This contrasts previous results that have reported low treatment rates for sleep problems in children with an ID (Didden et al., 2002; Wiggs & Stores, 1996b). This finding might be explained by the fact that the treatment question was worded so as to allow participants to include any treatment attempted, including self-help treatment, as opposed to enquiring solely about professional treatment that had been sought. It was not possible to know how many parents had obtained professional advice, and from whom, as opposed to those who had attempted to solve their child's sleep problem of

their own accord. Certainly, some parent explanations of treatment indicated that professional advice had not been sought.

Therefore, it seems that parents are likely to try and solve their child's sleep problem themselves instead of seeking professional advice. This finding is remarkable given the severity and persistence of sleep problems in children with an ID, and from Study 1 it is not possible to discern a clear reason for this. Perhaps the parent tries to treat the child's sleep problem, and when they are unsuccessful comes to assume that the sleep problem cannot be treated. Alternatively, because of the lack of suitably qualified health professionals in the field of sleep problems (Stores & Wiggs, 1998), or because professionals seldom address the issue of sleep problems (Bartlett et al., 1985; Chervin, 2001), the parent may assume that this means the child's sleep problem cannot be treated, and is therefore unlikely to seek treatment.

In Study 1, parent ratings of treatment success were poor for all treatment methods. This finding causes concern given the fact that parents seem reluctant to seek professional treatment for their child's sleep problem in the first place (Robinson & Richdale, 2004; Wiggs & Stores, 1996b). More importantly, this finding is alarming because the literature indicates such sleep problems can be effectively treated (Richdale & Wiggs, 2005). Thus, those parents who do seek treatment are not able to access the correct form of intervention.

Furthermore, in Study 1 behavioural intervention received poor success ratings, despite the fact that it has been reported as the most effective method of intervention for such sleep problems (Wiggs & Stores, 1996b). These results suggest that either parents have been given incorrect treatment advice from professionals, a finding that has been reported previously (Wiggs & Stores, 1996b), or that parents have attempted treatment themselves and have been unsuccessful. Another possible

reason for the poor treatment success of behavioural intervention may relate to the method used to classify interventions. A lack of information regarding many of the treatments tried made it difficult to discern whether or not an intervention was indeed behavioural in nature. This is further exacerbated by the fact that it was hard to distinguish whether or not treatment tried involved professional assistance. This indicates that sleep problem education of both parents and professionals is required in order to ensure that empirically validated treatments are recommended and correctly implemented for families who have a child with an ID and a sleep problem.

Given the significant associations that have been reported between sleep problems in children with an ID, daytime behaviour of the child, and maternal stress (Didden et al., 2002; Quine, 1991; Quine, 2001; Richdale et al., 2000), it is important to consider the effects that sleep intervention has on these areas of functioning. Bramble (1997) used behavioural intervention to treat the sleep problems of children with an ID and reported concomitant improvement in the child's daytime behaviour, maternal stress and maternal sleep. However, other studies have not found an improvement in child daytime behaviour (Thackery & Richdale, 2002) and maternal stress upon successful treatment of the child's sleep problem (Weiskop, 2001; Wiggs & Stores, 1999). This may be because parents do not generalise the intervention skills they have learned across settings and to other behaviours. Study 3 involved examining whether a general parent-training program was effective in treating sleep problems in children with an ID. Results showed that the intervention was effective in treating some but not all of the children's sleep difficulties, and that daytime behaviour improved for some but not all of the children: Parent stress, sense of confidence, and perceived control showed modest improvement.

For two of the three parents involved in Study 3, substantial improvement in the child's targeted sleep behaviour occurred, while slight improvement occurred for the third child. The parents were happy with the improvement shown and at follow-up none of the parents considered their child to have a sleep problem. The target daytime behaviour (compliance to parent requests) also improved at post-intervention, with improvements maintained at three-month follow-up for two children. However, the results also indicated that only slight improvements were obtained in relation to other sleep behaviours that were not specifically targeted in the intervention, such as sleep quality, co-sleeping, and the child falling asleep in their own bed. Furthermore, while scores on daytime behaviour improved for two of the children, all three children still scored in the clinical range at follow-up.

There are two possible reasons why the children's sleep did not show improvements across all of the sleep behaviours that were measured. Firstly, it is possible that some of the sleep behaviours measured were not a problem for the parents, and thus change in these sleep behaviours was not important. The parent targeted the sleep behaviour that was of primary concern and applied the strategies in relation to this. For other sleep behaviours they may not have applied the strategies because they were not thought to be required. Secondly, medications being taken by the child may have negatively influenced the duration and quality of the children's sleep. Two of the children in Study 3 were taking medications that may have side effects on sleep.

The results from Study 3 suggest that sleep problems are best treated using a specific sleep intervention program as opposed to a general parent-training program for behaviour management. Treatment that is specifically tailored to educate families about sleep problems in children with an ID as well as providing strategies to

alleviate the sleep problem may be more useful for parents and may lead to more substantial improvements in the child's sleep behaviour. However, it is important to note that Study 3 was the first study of this kind to examine the treatment of sleep problems using a general parent-training program as opposed to a specific sleep intervention. One parent out of the three reported substantial improvements in both the child's sleep and daytime behaviour in Study 3, suggesting that generalisation did occur for this parent. This is further evidenced by the fact that this parent's ratings of perceived control over the child's sleep behaviour, and over the child's daytime behaviour both displayed strong increases. By follow-up, both perceived control ratings were extremely high, having almost doubled. This is compared to the other two parents who showed an increase in perceived control over sleep behaviour, and no increase, and a slight increase in perceived control over their child's daytime behaviour respectively.

There are several possible reasons to explain why one parent demonstrated generalisation across target behaviours after completion of a training program, while the other two parents did not. These reasons can be grouped into three factors: Program related factors, extrinsic/situational factors, and intrinsic parental factors. Program related factors refer to components within the program that may not be conducive to the facilitation of generalisation across behaviours. Given that the Signposts program (Hudson et al., 2003) is designed to help parents manage a wide range of difficult behaviours, this reason seems unlikely. The Signposts program teaches theoretical behavioural principles, employs a range of examples during video and workbook exercises, addresses problem solving skills, as well as planning for high-risk difficult behaviour situations in a variety of home and community settings. All three parents received the same intervention and attended all sessions of the

intervention program, and the author, who implemented the program, is a trained Signposts facilitator.

Extrinsic or situational factors relates to certain barriers that prevented parents from being able to generalise the skills taught as a result of what is happening in their day to day life. Some of these may include not completing the set homework tasks, the amount of time the parent had with the child, whether or not the child was in respite, the amount of time the parent spent working, time pressures due to other commitments, the amount of interest shown in the program by the non-attending parent/partner, and parental stress due to other issues.

Intrinsic parent factors relate to specific characteristics of the parent that might effect whether or not the parent demonstrates generalisation across behaviours. Such factors may include the level of motivation of the parent, their educational level, their personality, lack of success with previous interventions, and the attitudes they possess towards their child's sleep and other behaviour problems. Those parents who view their child's sleep and daytime behaviour as a result of the child's disability may be less likely to apply the behavioural management strategies, or may be less likely to recognise the relevance of the strategies to other difficult behaviours.

Additional improvements were reported for the parent who demonstrated generalisation across behaviours. This parent had initially reported low levels of parenting satisfaction and efficacy, but after the intervention these levels had increased greatly and were within the normal range. Furthermore, this parent displayed an improvement in ratings of daily hassles with further gains demonstrated at follow-up. It is difficult to discern whether the improvement in sleep, or the

improvement in daytime behaviour, or both was related to a decrease in stress for this parent.

Perceived control over the child's sleep behaviour did improve for all parents, and these parents no longer considered their child to have a sleep problem. The parent who showed the highest score and the most improvement on perceived control reported the most improvement in their child's sleep. This parent also showed a substantial improvement in perceived control over their child's daytime behaviour, compared to the other two parents who showed little and no improvement on this rating. This suggests that parent ratings of perceived control over the child's sleep is directly related to the level of sleep improvement shown, and hence is an important factor to take into consideration when conducting sleep intervention. Perceived control may be used as a simple and rapid method of checking on parent progress during and after an intervention program. This way, parents who report little to no change in perceived control could be easily identified, and the issues concerning a lack of improvement in the child's sleep problem could be more quickly acknowledged and addressed.

In the same way, perceived control measures may also be useful in assessing whether generalisation across behaviours is occurring. Parents who do not report a corresponding increase in control over their child's daytime behaviour could be approached during an intervention program and various methods could be undertaken to further facilitate generalisation across behaviours.

In conclusion, the results from Study 3 suggest that a general parent-training program can be effective in treating the sleep problems for some children with an ID, and that generalisation across behaviours can also occur. Involvement in such a program can have additional effects on the parent's perceived control over their

child's sleep and daytime behaviour, as well as parental hassles, and levels of parenting satisfaction and efficacy. These results are based on the findings of just three families and can be considered as preliminary results. Further studies need to be considered before firm conclusions can be drawn.

7.2 Methodological considerations

The context of this research needs to be taken into account when considering the results and the ensuing implications of these studies. There were some limitations that were common across the three current studies. Firstly, the low number of participants involved in the research implies that the results may not be reflective of the population at large. Both Study 1 and Study 2 had return rates of approximately 30%. Of 809 questionnaires that were distributed across special schools and special developmental schools in Melbourne for Study 1, 243 parents participated in the study. Of these, 76 parents also participated in Study 2. There were 20 parents of children with an ID and a sleep problem that participated in Study 2, and only 3 were involved in the intervention in Study 3. With the high prevalence, intensity, and negative impact of sleep problems in children with an ID, one would expect more parents to be involved in the research.

The extensive range in reply rates (from 15% to 58%) across the schools suggests that the method of recruitment may have been related to the lower than expected participation rates. There was a wide range in the level of willingness across schools to have their parents informed about the study. Perhaps an alternative would have been to approach various disability organisations whose board and constituent members value research, and are willing to act as a medium for recruitment. Although, of those who completed the Study 1 questionnaire only

approximately 30% went on to participate in Study 2. This low rate of interested respondents may be due to the fact that parents of children with an ID do not have time to be involved in research due to other more prevalent demands.

Secondly, there was a lack of homogeneity regarding the types of disabilities that the children displayed. While Study 1 and Study 2 allowed for some comparisons to be made across disability types, the low numbers in some of the groups made it difficult to perform meaningful comparisons across the broad age ranges. Approaching special schools and special developmental schools made it impossible to know how many parents of children with a certain type of disability would participate in the research. To overcome this, future research may be better suited to approach specific disability organisations in order to gain better access to parents who have children with specific disabilities. Study 1 and Study 2 did examine sleep by disability, however, the group numbers in Study 2 were quite low.

Thirdly, the travel factor involved appeared to be an issue for at least four parents who were interested in participating in Study 3. As the previous studies had approached parents from a range of geographical locations in Melbourne, some parents had to travel a long distance to attend the program. Perhaps a better alternative would have been to offer the programs in several locations, or to perform the intervention using the individual face-to-face mode of delivery as opposed to the group method of delivery. Thus, the intervention could have been delivered to the parent at their home and at a time that suited them. This change in methodology may have increased the number of participants in Study 3. Furthermore, some parents may not have participated in Study 3 due to the time commitment required to complete the intervention. The intervention program involved six sessions over an eight week period with each session lasting 2.5 hours.

7.3 Implications for future research

These results suggest that there are several research and clinical areas of importance to be further considered in relation to sleep problems in children with an ID. These include parental report of sleep disturbance and recognition of a sleep problem, parental factors that influence whether or not a parent identifies that their child has a sleep problem, and the use of a general parent-training program to treat sleep problems in children with an ID compared to using sleep-specific intervention.

It seems that parents who have a child with an ID are unlikely to view a sleep disturbance as a behavioural manifestation, but tend to believe the disturbance is a result of the child's disability or medical condition (Bramble 1996; Robinson & Richdale, 2004; Stores, 2001a). This means that parents are unlikely to visit a health professional specifically to address the sleep problem. The frequency, intensity, persistence, and wide-ranging negative impact of such sleep problems requires that they be addressed and treated with empirically validated interventions by suitably qualified professionals. In order for this to occur, it is important that health professionals enquire about children's sleep. Unfortunately, at present many health care professionals do not enquire about sleep problems in children, and may offer incorrect treatment options when they do (Bartlett et al., 1985; Blunden et al., 2004; Chervin et al., 2001; Wiggs & Stores, 1996b). Therefore, education in the child health professional sector is required to overcome these inadequacies.

Furthermore, additional research in relation to parental recognition of sleep problems in children with an ID is warranted. It is important to know why some parents will view their child's sleep disturbance as a problem, yet others will not. Parents who do not view their child's sleep to be a problem will not come to the

attention of professionals. Child, parent, or environmental factors may be related to parental recognition of a sleep problem, and these require further consideration. Additionally, the notion of parent recognition of a child sleep problem changing over time needs to be explored. Some parents may change their opinion about whether or not their child's sleep constitutes a problem, and there may be some common reasons why this occurs.

It would be useful to conduct a randomly allocated study comparing the effectiveness of a specific sleep intervention as opposed to a general parent-training program. Such a study would help clarify whether or not a general parent-training program is as effective as a specific sleep intervention in treating the sleep problems of children with an ID. It would also address whether parents who undertake the general training program report improvements in factors associated with the sleep problems in children with an ID, such as child behaviour, and parent stress.

Another issue to be considered in such an experiment is being able to predict the optimal type of intervention for each parent. It may be that certain parents are suited to one type of intervention over the other. Some parents may be able to undertake a specific sleep intervention, and then generalise to daytime behaviour, while others may require the general parent-training program in order for this to occur, and other parents may require both intervention programs, or may be best suited to undertake separate interventions designed to treat each target behaviour separately. This would involve testing for factors that would distinguish the optimal type of treatment for each parent. These factors may be related to the child (e.g., type of sleep and behaviour problems, type and severity of ID, associated medical condition), may be intrinsic characteristics that the parent possesses (e.g.,

personality, perceived control), or may relate to the family's circumstances (e.g., parent work schedule, interventions that have been tried previously).

Addressing these three areas of future clinical and research importance would be of direct benefit to families who have a child with an ID and a sleep problem. At present, these families are left to endure a significant problem that can have multiple negative effects on both the child and the family. Parents appear to be largely unsupported on this issue and remain unaware that effective interventions that can be tailored to meet their needs are available.

7.4 Conclusion

Findings from Study 1 indicate that night settling, night waking, early waking and co-sleeping in children with an ID are a common occurrence, however, a number of parents do not consider this to constitute a sleep problem. While a higher than expected number had sought treatment for their child's sleep problem, treatment ratings were generally very low. This indicated that parents either received inappropriate advice, misunderstood or did not follow through with the advice given, or attempted to treat the problem themselves (e.g., over the counter medication, implementing their own behavioural strategies to ameliorate the problem).

Results from Study 2 suggest that for some parents' perception regarding their child's sleep problem changes over time. There may be situational factors related to the child, parent, family context that lead parents to change their mind over time regarding whether or not they would consider their child to have a sleep problem. Parents in the unrecognised sleep problem group had a higher level of perceived control than parents in the recognised sleep problem group and parents in the no sleep problem group, and also reported that their child slept longer than

children in the recognised sleep problem group. The daytime behaviour of the child, parent stress, locus of control, personality, and efficacy in the parenting role did not differentiate the parents in the unrecognised sleep problem group from the parents in the recognised sleep problem group and the no sleep problem group.

Study 3 showed that a general parent-training program used to treat sleep problems in children with an ID was partially successful. At three-month follow-up all parents reported that their child no longer had a sleep problem, however, improvement was generally seen only for the targeted sleep behaviour, and for two parents minimal improvements in the child's daytime behaviour, parent stress, and parenting satisfaction and efficacy occurred. One parent reported improvement in relation to child sleep and behaviour variables as well as parent variables.

Sleep problems in children with an ID are a complex issue. Further research is required in order to gain a full understanding of the complexities and ensure that effective treatment can be tailored to meet the needs of parents and their children. Furthermore, parents and professionals require education about the importance of prevention and treatment of such sleep problems, and the most appropriate treatment methods that are available. Having a child with a disability does not automatically equate to a lifelong sleep problem. A number of intervention options can and should be explored by parents and professionals in order to improve the child's sleep, and the quality of life of the entire family.

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Appendix A. Plain Language Statement

Plain Language Statement: Project Information

The role of parent and child characteristics in relation to sleep behaviour for children with an intellectual disability.

Bundoora Campus
 PO Box 71
 Bundoora 3083
 Victoria Australia

Tel +61 3 9925 7376
 Fax +61 3 9925 7303
<http://www.rmit.edu.au/departments/ps/>

Dear Parent / Carer,

My name is Anthony Robinson. I am a student at RMIT University, Bundoora, studying a Doctorate of Psychology. As part of this course I am investigating child and parent characteristics and their relation to sleep behaviour.

Enclosed is a brief questionnaire that contains questions regarding your child's sleep behaviour, and will take no more than 10 minutes to complete. The questionnaire involves providing general information about your child, as well as some specific information regarding your child's sleep behaviour.

Once you have completed the questionnaire, please seal it in the envelope provided and return it to your child's school. A return box will be placed at the reception.

The questionnaire also gives you the option to participate in further research regarding sleep behaviour in children as well as their families. This research needs families of children with and without sleep difficulties, and would involve the completion of a number of questionnaires (at home, over the period of a fortnight) taking no more than 90 minutes to complete. In addition, a one-hour interview will be conducted where a questionnaire about your child's general functioning is administered. For your participation in this research, a written report of the results from this questionnaire would be made available to you if you wish.

Your participation is greatly appreciated, but is in no way compulsory. Participating in this research is voluntary and only my supervisors and I will have access to your data. You will not be identified.

The results from this study may be written up for publication in a scientific journal or as a conference presentation. A brief report of the findings from the study will be provided to your school for dissemination to parents.

If you have any queries concerning the research please contact me on 9925-7376 and leave a message (I will get back to you), or phone my supervisor, Dr. Amanda Richdale on 9925-7366.

Thank you for your time.

Anthony Robinson (Grad. Dip. Psych)
 Doctorate of Psychology Student

Dr. Amanda Richdale (PhD)
 Supervisor

Jan Matthews (Med)
 Supervisor

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745.

Appendix B. Sleep Questionnaire

Today's Date: / / 01

Children's Sleep Survey.

The purpose of this survey is to gather information about sleep in young children. Please take a few minutes to complete this survey. Any information you provide will remain strictly confidential. The survey will only take 2-5 minutes to complete.

1) What is your relationship to the child? _____

Child Information:

2) Date of birth ____ / ____ / ____

3) Sex: Male ☐ Female ☐

4) Diagnoses: (Please circle)

None Autism Spectrum Disorder

Intellectual Disability Pervasive Developmental Disorder

Autism Asperger's Disorder

Down's Syndrome Attention Deficit Hyperactivity Disorder

Other _____

5) Does your child have any other medical condition?

Epilepsy ☐ Asthma ☐ Other _____

6) Is your child currently taking any medication, and if so, what is this medication being taken for? (Please list if applicable):

7) On average, how many hours per night does your child sleep? _____

8 a) Does your child have: Tick if applicable:

☐ Problems settling to sleep ☐ Waking during the night

☐ Early morning waking ☐ Other _____

☐ None

8 b) How severe is your child's sleep disturbance (Please tick):

☐ Mild ☐ Moderate ☐ Severe

9) Is your sleep disrupted due to your child's sleep?

☐ Yes ☐ No

10) Do you believe your child has a sleep problem?

☐ Yes ☐ No (If no go to Q.15)

11) How long has your child had this sleep problem? _____

Survey continues. Please turn page over →

12) If your child has been diagnosed with a sleep disorder, what diagnosis did they receive? _____

13) What has been tried in the past to overcome your child's sleep problem? (Please tick all that are applicable).

- ☐ Never sought treatment
- ☐ Behavioural intervention program
- ☐ Medication (Please specify) _____
- ☐ Herbal treatment (Please specify) _____
- ☐ Other (Please specify) _____

14) How successful was this treatment?:

Type of treatment 1: _____

Place a cross on the line to indicate treatment success.

Not very _____ Very
successful successful

Type of treatment 2: _____

Place a cross on the line to indicate treatment success.

Not very _____ Very
successful successful

Type of treatment 3: _____

Place a cross on the line to indicate treatment success.

Not very _____ Very
successful successful

15) Would you be interested in further research regarding sleep, as well as parent and child characteristics?

☐ Yes ☐ No

If yes, please give following details, so that you can be provided with further information:

Contact number(s): Home: _____

Work: _____

Postal address:

E-mail address: _____

Convenient contact time(s): _____

Thank you.

Appendix C. RMIT Human Research Ethics Committee Approval for Study 1 and 2



APPLIED SCIENCE

MEMORANDUM

FROM: Lina Papillo, Secretary, Faculty Human Research Ethics Sub-Committee
PHONE: 9925-6102
FAX: 9925-6107
E-MAIL: lina.papillo@rmit.edu.au

Faculty of Applied Science

Bundoora Campus
 PO Box 71
 Bundoora 3083
 Victoria Australia

Tel +61 3 9925 6102
 Fax +61 3 9925 6107
 E-mail
 wendy.fleming@rmit.edu.au
 http://www.rmit.edu.au

TO: Anthony Robinson, Department of Psychology & Disability Studies
DATE: 31 May 2001
RE: Application for ethics approval
CC: Dr Amanda Richdale, Department of Psychology & Disability Studies; Dr John Reece, Chair, Faculty of Applied Science Human Research Ethics Sub-Committee

Your project, titled *Sleep Problems in Children with an Intellectual Disability: The Role of Child and Parent Characteristics*, has been considered by the Faculty of Applied Science Human Research Ethics Sub-Committee. You self-rated the project as NR (i.e., no risks above the everyday norm) and the Sub-Committee agreed with that rating. Some required changes to your application were brought to your attention in my memo to you of 9 May 2001. You have addressed all of the issues raised in that memo appropriately. Therefore, you may consider your project, as it is described in your revised application, **APPROVED** for a period of three years from the date on this memo.

Should your project not be completed within three years, you should apply for an extension of approval. Also, you should be aware that there is a requirement to provide a report at the end of the project. Pro-formas for both tasks are available from me.

Let me take this opportunity to wish you all the best with your research. If any issues regarding ethics arise during the running of the project, please do not hesitate to contact Dr Reece.

Sincerely

Lina Papillo
 Secretary, Faculty of Applied Science Human Research Ethics Sub-Committee

Appendix D. Department of Education (Victoria) Approval for Study 1 and 2



Department of Education, Employment and Training

Office of Schools

2 Treasury Place
East Melbourne, Victoria 3002
Australia

GPO Box 4367
Melbourne, Victoria 3001
Australia

Telephone +61 3 9637 2000
DX 210083

*School Community Support Branch
Level 2, 33 St Andrews Place
Telephone (03) 9637 2349
Facsimile (03) 9637 2180*

SOS001780

24 April 2001

Mr Anthony Robinson
Plenty Road Bundoora
PO Box 71
Bundoora 3083

Dear Mr Anthony

Thank you for your application of 26 March 2001 in which you request permission to conduct a research study in government schools titled: *Sleep Problems in Children with an Intellectual Disability: The Role of Child and Parent Characteristics*.

I am pleased to advise that on the basis of the information you have provided your research proposal is approved in principle subject to the conditions detailed below.

1. Should your institution's ethics committee require changes or you decide to make changes, these changes must be submitted to the Department of Education, Employment and Training for its consideration before you proceed.
2. You obtain approval for the research to be conducted in each school directly from the principal. Details of your research, copies of this letter of approval and the letter of approval from the relevant ethics committee are to be provided to the principal. The final decision as to whether or not your research can proceed in a school rests with the principal.



3. No student is to participate in this research study unless they are willing to do so and parental permission is received. Sufficient information must be provided to enable parents to make an informed decision and their consent must be obtained in writing.
4. As a matter of courtesy, you should advise the relevant Regional Director of the schools you intend to approach. An outline of your research and a copy of this letter should be provided to the Regional Director.
5. Any extensions or variations to the research proposal, additional research involving use of the data collected, or publication of the data beyond that normally associated with academic studies will require a further research approval submission.
6. At the conclusion of your study, a copy or summary of the research findings should be forwarded to me at the above address.

I wish you well with your research study. Should you have further enquiries on this matter, please contact Louise Dressing, Senior Research Project Officer, School Community Support Branch, on 9637 2349.

Yours sincerely



JOHN ALLMAN
A/Manager
School & Regional Operations

encl.

Appendix E. Current Medications Taken by Participants. Class, Purpose for use and Sleep Side Effects

Medication	Action	Frequency	Reason Given why Child Taking Medication	Sleep Side Effects
Antipsychotic				
Haloperidol	Butyrophenone psychotropic	2	Behaviour management	D, I, Se
Risperidone	Benzisoxazole derivative	7	Behaviour management	I
Thioridazine Hydrochloride	Piperidine phenothiazine	2	Mood stabiliser, antianxiety	D, S
Pericyazine	Psychotropic	1	Behaviour management	D, I, PSE
Antidepressant				
Fluvoxamine maleate	SSRI	2	Obsessive compulsions	I, So
Sertraline	Oral antidepressant	1	Weight problem with food	I
Fluoxetine	Oral antidepressant	1	Anxieties and obsessions	I, So, AD, SD
Antianxiety				
Diazepam	Benzodiazepine derivative	1	Muscle Relaxant	D
Clobazam	Anxiolytic agent	4	Anxiety and sleep disturbance	D, I, Se
Other CNS Agents				
Dexamphetamine Sulfate	Sympathomimetic amine of the amphetamine group	4	Attention Deficit Hyperactivity Disorder (ADHD)	I
Methylphenidate Hydrochloride	Central nervous stimulant	8	ADHD	D, I
Anticonvulsant				
Sodium Valproate	Anticonvulsant, antipsychotic	14	Epilepsy	D, Se
Lamotrigine	Antiepileptic	11	Epilepsy	I, So
Clonazepam	Anticonvulsant that exhibits properties characteristic of the benzodiazepine class of drugs	3	Epilepsy	D, So, T
Vigabatrin	Anticonvulsant	2	Epilepsy	D
Carbamazepine	Antiepileptic, neurotropic, and psychotropic agent	11	Epilepsy	D
Topiramate	Antiepileptic	1	Epilepsy	So
Ethosuximide	Reduces epileptiform attacks	1	Epilepsy	D, SD, NT

Neurontin	Treatment of partial seizures	2	Epilepsy	D, SE
Topamax	Controls abnormal nerve impulses in the brain	1	Epilepsy	So, D
Antihistamine				
Trimeprazine Tartrate	Antihistaminic, antipuritic, and sedative	1	Sleep	D
Topical Nasopharyngeal				
Budesonide	Anti-inflammatory	1	Help settle scar tissue	T
Thyroid & Antithyroid Agents				
Thyroxine Sodium	Major component of normal thyroid secretions	1	Overactive thyroid	I, SD
Carbimazole	Antithyroid effect	1	Overactive thyroid	None
Antihypertensive Agent				
Nifedipine	Calcium antagonist	1	Improved circulation	None
Bronchodilator Aerosol				
Ipratropium bromide	Anticholinergic bronchodilator	1	Asthma	None
Salmeterol Xinafoate	Bronchodilator	1	Asthma	None
Salbutamol Sulfate	Adrenoceptor stimulant	4	Asthma	None
Preventive Aerosol & Inhalant				
Salmeterol Xinafoate /	Adrenoceptor agonist, and anti-inflammatory	2	Asthma	None
Fluticasone Propionate	Glucocorticoid activity, and anti-inflammatory	4	Asthma	None
Fluticasone Propionate	Corticosteroid	1	Allergic rhinitis	None
Budesonide				
Detoxifying Agent, Antidotes				
Desferrioxamine Mesylate	Chelating agent	1	Iron intoxication	None
Antidiarrhoeals				
Loperamide Hydrochloride	Antidiarrhoeal agent	1	Hirschsprung's disease	None
Antihypertensive Agent & Antimigrane Preparation				
Clonidine Hydrochloride	Antihypertensive agent, migraine prophylaxis	5	Sleep, Throat infection, to relax to go to sleep,	D

Muscle Relaxant				
Dantrolene Sodium	Muscle relaxant	1	Relax muscles	D
Baclofen	Antispastic agent	1	Reduce spasticity	D, I, Se, N
Hyperacidity, Reflux, Ulcers				
Cisapride	Gastrointestinal prokinetic agent	2	Gastric reflux / antacid	None
Ranitidine Hydrochloride	Histamine receptor antagonist	1	Reflux	None
Reflux Medication	Neutralises stomach acid	1	Reflux	None
Mylanta	Neutralises stomach acid	1	Reflux	None
Expectorants, Antitussives, Mucolytics, Decongestants				
Brompheniramine Maleate / Phenylephrine hydrochloride	Decongestant, and antihistamine action	1	Runny nose	None
Cough Medicine	Symptom relief	1	Cough	D
Antimetabolites				
Methotrexate	Antimetabolite, and antineoplastic agent	1	Arthritis	D
Movement Disorders				
Benzhexol Hydrochloride	Inhibition of parasympathetic nervous system, and relaxing effect on smooth musculature	1	Saliva control	None
Benztropine Mesylate	Anticholinergic, and antihistaminic effects	1	To counter other medications	None
Over the Counter Medications				
Eye Drops		1	Eyes	None
Antibiotics		3	Ear infections, nail infections,	None
Hormones				
Growth Hormone	Stimulates growth of bone, tissues, blood cells, and internal organs	1	Post splenectomy	None
Insulin	Regulates glucose use in the body	1	Diabetes	None
Secretin		2	Autism, anxiety, eczema, tourettes, and for gastrointestinal disorder	Unknown

Melatonin		1	To adjust body clock	Unknown
Alternative Medications				
Multivitamins	Action varies	4	Appetite, stamina and energy, metabolism	None
Copper Histadine	Aids collagen formation, and plays a role in cell respiration	1	Intramuscular and metabolism	None
Fish Oil	Anti-inflammatory, anti-thrombotic, anti-platelet, neurological	1	Metabolism	None
Primrose Oil	Increases cellular metabolism	1	Metabolism	None
Herbal Tonic	Action varies according to formula	1	Digestion and sleep settling	Unknown
Homeopathic	Action varies according to formula	2	Autism, anxiety, eczema, tourettes, and general health	Unknown
Unlisted Medications				
Lientolin		1	Autism	Unknown
Dimethlyglycine		1	Autism	Unknown
Epilips		2	Epilepsy	Unknown

AD = Abnormal Dreams; D = Drowsiness; I = Insomnia; NT = Night Terrors; PSE = Paradoxical Sleep Effect; SD = Sleep Disorder; Se = Sedation; So = Somnolence; T = Tiredness. Action information taken from Medical Publishers Association of Australia. (1996).

Information in table from MIMS unless otherwise stated.

^a Patient Drug Facts 2006

Appendix F. Treatments Tried to Alleviate Sleep Problem

Treatment Method	Frequency
Medication (<i>n</i> = 31)	
Pherergan	5
Vallergan	4
Melatonin	2
Unspecified	2
Vallergan and Temazepam	1
Vallergan	1
Phenergan and Valerian	1
Vallergan and Phenergan and Bedwetting Spray	1
Vallergan	1
Ritalin	1
Dimetap to Relieve Nasal Congestion	1
Mellaril and Catapres	1
Increasing Epileptic Medication	1
Antihistamine from Germany	1
Altering Time of Epileptic Medication	1
Mogadon, Chloral Hydrate, and Mellatonin	1
Chloral Hydrate	1
Vallergan, Vallergan Forte, and Temtabs	1
Largactil and Mellatonin	1
Zantae (antireflux)	1
Mogadon and Chloral Hydrate	1
Catapres	1
Behavioural (<i>n</i> = 24)	
Unspecified	16
Sleep in Parent's Bed	1
Mother Sleeps in Child's Bed	1
Keep up as Late as Possible	1
Keep From Daytime Nap	1
Environment Modification	1
Music to Settle, Sleep With Sister, Bath, Hot Water Bottle	1
Crying Himself to Sleep, Gradual Checking	1
Routine Alterations and Retraining	1
Herbal (<i>n</i> = 8)	
Natural Therapist	2
Herbs to calm down not actually sedate	1
Homeopathic	1
Peppermint Tea	1
Hops	1
Kalm Kids	1
Essential Oil Drops on Pillow (Relaxing)	1

Other ($n = 5$)	
Music tapes and cd	1
Toys	1
Given Enough Food Before Bedtime	1
CPAP Machine	1
Operation and Time at early parenting centre	1

Appendix G. Demographic Information Sheet

1/ Today's date: / /

2/ Child's date of birth: / /19

3/ Your relationship to the child _____

4/ Your country of birth _____

5/ The country of birth of the child's other parent _____

6/ Your child's country of birth _____

7/ Primary language spoken at home _____

8/ Your level of education _____

9/ Level of education of child's other parent/carer _____

10/ Your current occupation _____

11/ Current occupation of child's other parent _____

12/ Number of children in the family _____

13/ Child's school: **Special School** **Special Developmental**
School

14/ Do you think your child has a sleep problem: **Yes** **No**

Please give a brief explanation for this answer: _____

15/ In relation to your child's diagnosis:

When (year) was your child assessed: _____

Place of assessment (eg hospital): _____

What was the specific diagnosis given: _____

*Note: If possible, a photocopy from the page of the report that states this diagnosis would be very helpful.

Appendix H. Plain Language Statement Study 2



PSYCHOLOGY AND
DISABILITY STUDIES

Bundoora Campus
PO Box 71
Bundoora 3083
Victoria Australia

Tel +61 3 9925 7376
Fax +61 3 9925 7303
<http://www.rmit.edu.au/departments/ps/>

Plain Language Statement: Project Information

Sleep problems in children with an intellectual disability: The role of child and parent characteristics.

Dear Parent / Carer,

My name is Anthony Robinson. I am a student at RMIT University, Bundoora, researching child and parent characteristics and their relation to sleep behaviour.

Thank you for completing the screening questionnaire, and for choosing to participate in the second part of this study.

The research involves the completion of a number of questionnaires (enclosed) in relation to your child's sleep and behaviour, as well as questionnaires regarding your personality and family environment. The completion of the questionnaires will take approximately 100 minutes and can be completed at home. Once completed, the questionnaires can be returned via the reply paid self-addressed envelope that is provided.

Your participation, is appreciated, but is in no way compulsory. Participating in this research is voluntary and only my supervisor and I will have access to your data. You will not be identified.

The results from this study may be written up for publication in a scientific journal or as a conference presentation.

If you have any queries concerning the research please contact me on 9925 - 7376 and leave a message (I will get back to you), or phone my supervisor, Dr. Amanda Richdale on 9925 - 7366.

Should you agree to participate in the study, I will contact you to help with any queries that you may have.

Thank you for your time.

Anthony Robinson (Grad. Dip. Psych)
Doctorate of Psychology Student

Dr. Amanda Richdale (PhD)
Supervisor

Jan Matthews (Med)
Supervisor

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745.

Appendix I. Consent Form Study 2



PSYCHOLOGY AND
DISABILITY STUDIES

Bundoora Campus
PO Box 71
Bundoora 3083
Victoria Australia

Tel +61 3 9925 7376
Fax +61 3 9925 7303
<http://www.rmit.edu.au/departments/ps/>

DEPARTMENT OF: Psychology and Intellectual Disability Studies

FACULTY OF Science

Name of participant:

Project Title: Sleep Problems in Children With an Intellectual Disability: The
Role of Child and Parent Characteristics.

Name(s) of investigator(s): Anthony Robinson Phone 9925 - 7376

Amanda Richdale (Supervisor) Phone 9925 - 7366

Jan Matthews (2nd Supervisor) Phone 9925 - 7362

1. I have received a statement explaining the interview/questionnaire involved in this project.
2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.
3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.
4. I acknowledge that:
 - (a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.

- (b) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.
- (c) The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.
- (d) The confidentiality of the information I provide will be safeguarded. However should information of a confidential nature need to be disclosed for moral, clinical or legal reasons, I will be given an opportunity to negotiate the terms of this disclosure.
- (e) The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to schools and specialist centres. Any information that will identify me will not be used.

Participant's Consent

Signature:Date:.....

(Participant)

<p>Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745.</p>
--

Appendix J. Current Medications Taken by Participants. Class, Purpose for use and Sleep Side Effects

Medication	Action	Number Taking Medication	Reason Given why Child Taking Medication	Sleep Side Effects
Antipsychotic				
Haloperidol	Butyrophenone psychotropic	1	Behaviour management	D, I, Se
Risperidone	Benzisoxazole derivative	1	Behaviour management	I
Thioridazine Hydrochloride	Piperidine phenothiazine	2	Mood stabiliser, antianxiety	D, S
Pericyazine	Psychotropic	1	Behaviour management	D, I, PSE
Antidepressant				
Sertraline	Oral antidepressant	1	Anxieties and obsessions	I
Antianxiety				
Clobazam	Anxiolytic agent	1	Anxiety and sleep disturbance	D, I, Se
Other CNS Agents				
Dexamphetamine Sulfate	Sympathomimetic amine of the amphetamine group	3	Attention Deficit Hyperactivity Disorder (ADHD)	I
Methylphenidate Hydrochloride	Central nervous stimulant	1	ADHD	D, I

<hr/> Anticonvulsant					
Sodium Valproate	Anticonvulsant, antipsychotic	4	Epilepsy	D, Se	
Lamotrigine	Antiepileptic	3	Epilepsy	I, So	
Clonazepam	Anticonvulsant that exhibits properties characteristic of the Benzodiazepine class of drugs	2	Epilepsy	D, So, T	
Carbamazepine	Antiepileptic, neurotropic, and psychotropic agent	4	Epilepsy	D	
Ethosuximide	Reduces epileptiform attacks	1	Epilepsy	D,SD,NT	
<hr/> Antihistamine					
Trimeprazine Tartrate	Antihistaminic, antipruritic, and sedative	1	Sleep	D	
<hr/> Thyroid & Antithyroid Agents					
Thyroxine Sodium	Major component of normal thyroid secretions	1	Overactive thyroid	I, SD	
<hr/> Antihypertensive Agent					
Nifedipine	Calcium antagonist	1	Improved circulation	None	
<hr/> Bronchodilator Aerosol					
Salbutamol Sulfate	Adrenoceptor stimulant	1	Asthma	None	
<hr/>					

Preventive Aerosol & Inhalant				
Fluticasone Propionate	Glucocorticoid activity, and anti-inflammatory	1	Asthma	None
Hyperacidity, Reflux, Ulcers				
Reflux Medication	Neutralises stomach acid	1	Reflux	None
Mylanta	Neutralises stomach acid	1	Reflux	None
Expectorants, Antitussives, Mucolytics, Decongestants		1		
Cough Medicine	Symptom relief	1	Cough	D
Antimetabolites				
Methotrexate	Antimetabolite, and antineoplastic agent	1	Arthritis	D
Movement Disorders				
Benzhexol Hydrochloride	Inhibition of parasympathetic nervous system, and relaxing effect on smooth musculature	1	Saliva control	None
Over the Counter Medications				
Eye Drops		1	Eyes	None
Alternative Medications				
Multivitamins	Action varies	2	Appetite, stamina and energy, metabolism	None

Copper Histadine	Aids collagen formation, and plays a role in cell respiration	1	Intramuscular and metabolism	None
Fish Oil	Cellular respiration	1	Metabolism	None
Primrose Oil	Increases cellular metabolism	1	Metabolism	None
Herbal Tonic	Action varies according to formula	1	Digestion and sleep settling	Unknown
Medication not Specified				
	-	4	Epilepsy	Unknown
	-	1	Throat infection	Unknown
	-	1	Skin Condition	Unknown
Unlisted Medications				
Dimethlyglycine		1	Autism	Unknown

AD = Abnormal Dreams; D = Drowsiness; I = Insomnia; NT = Night Terrors; PSE = Paradoxical Sleep Effect; SD = Sleep Disorder; Se = Sedation; So = Somnolence; T = Tiredness

Note: Information obtained from Facts and Comparisons (2005)

Appendix K. Reasons Given by Parents to Explain why Their Child has/does not have a Sleep Problem

Child ID	Child's Age	Child's Diagnosis	Reason given to explain why parent/carer thinks child does/does not have a sleep problem	Does explanation indicate sleep is problematic
Sleep Problem Group ($n=20$)				
1	12	PDD & CP	Very erratic sleeper, sometimes good, sometimes not. Doesn't understand the concept of lying quietly to go to sleep	Yes
3	9	PDD	Very hard to get to sleep, nights he wakes up crying	Yes
10	4	PDD	Mostly sleeps too much, disturbed sleep, sleeps deeply, breathes less when asleep, nightmares/screaming, talking when asleep, grinds teeth, night sweats, takes a long time to wake up properly, often grumpy if woken	Yes
51	7	PDD	He wakes up at 3 in the morning some nights, and he's up till 6.30	Yes
61	11	PDD	Usually a short span sleeper, wakes goes to the toilet then plays for 1 hr to re-settle. Co-sleeps	Yes
74	13	Pdd	Without medication would not sleep at all	Yes
104	11	ID	She sometimes does not sleep in midnight due to excitement	Yes
117	8	Oth ID	Every night up at least 2-3 times, cries/screams	Yes
140	6	DS	Doesn't sleep, up and down all night	Yes

155	13	CP	Irregular sleep pattern, frequently wakes at night, naps during day, gets day and night mixed up, infrequent apnoea	Yes
157	6	CP	Due to his condition, CP	Clear explanation not given
168	16	DS	I think it is more of a behavioural problem than a sleep problem, frequently won't do what is asked of her	Yes
174	15	DS	Has vivid frightening dreams. Sometimes has trouble going to sleep, sometimes wakes during the night scared. Often needs light on at night	Yes
199	11	ID	Sleep is disrupted most nights, has been doing this since birth, makes a 'rah' noise to get back to sleep	Yes
210	17	CP	Does not sleep through very often. Rubs his face into the corner of the bed/wall. Traumatizes himself. Catnaps in his wheel chair	Yes
211	12	Oth ID	Finds it hard to settle, though easier now on medication, can't sleep through night	Yes
227	8	ID	Difficult to settle, difficult to re-settle once woken. Can't seem to go to sleep, very early riser (5.45 common), troubled sleep, appears agitated, restless in sleep, any change in bed requires medications (i.e. holidays)	Yes
232	6	DS	Wakes up at night, been doing this since the age of 2	Yes
234	9	PDD	Unable to sleep without interruption and help	Yes

244	5	DS	Co-sleeping every night, but don't really consider it a problem, more a habit	Yes
<hr/>				
No Sleep Problem Group ($n=36^a$)				
9	9	PDD	Not disturbed through the night other than if he gets cold, or one off	No
12	10	PDD	Goes to bed when asked with little prompting	No
17	13	PDD	Sometimes I do, doesn't worry him & if you're not next to him it doesn't worry us either	Yes
18	5	PDD	Sleeps well does not wake during the night	No
22	6	DS	She goes to bed at 7.30-8 and wakes between 6-7. A little early in the morning but she's an early bird like her dad	No
32	9	PDD	Once get him into bed it's okay, getting him in is the problem. Sometimes puts himself to bed	Yes
44	7	PDD	We sometimes have trouble getting him to sleep, but once he is asleep there is usually no problem unless he is ill	Yes
55	6	PDD	He's a pretty normal sleeper	No
58	12	ID	Goes to bed at night, straight to sleep, up with alarm	No
78	16	ID	Does not wake at all, has not trouble getting to sleep	No
97	6	ID	Because apart from waking early, he sleeps like a baby	Yes
101	3	ID	Because he sleeps fairly well most of the time	Yes
102	7	Oth ID	When she is not in pain, quite rested in the morning relaxed	Yes

			and happy to play	
105	18	ID	Ever since very young goes to bed without any trouble and sleeps right through	No
108	11	ID	Simone sleeps well, wakes up with energy and will go to bed willingly. She may sleep more than a regular 11 year old	No
109	18	DS	She goes to bed at the same time. Sleep never disturbed unless sick	No
113	17	ID	He is epileptic and has seizures, irregular, epilepsy seems to be in line with lunar cycle, nocturnal seizures, apart from that he sleeps reasonably well	Yes
124	4	ID	Sleeps well during the night, has a good nights sleep	No
126	4	PDD	Because he doesn't understand our world, doesn't understand the way things happen	Yes
127	12	PDD	She goes to sleep quickly and stays asleep all night (as far as I know anyway). She sleeps a decent number of hours and wakes refreshed	No
133	4	PDD	Goes to bed late (routine) sleeps right through to 8. Couple of hours in the afternoon. Not disturbed	No
141	12	ID	Once he's asleep he mainly sleeps through the night	Yes
146	8	ID	Because she had problems when she was younger, now sleeps at night, not a very good sleeper but much better than it was	Yes

150	11	PDD	On average sleeps 10-12 hours a night, only odd night she doesn't	No
151	7	CP	Goes to bed at 7 and wakes up at 6, sleeps straight through	No
169	14	DS	Goes to bed at roughly the same time and goes to sleep with little fuss and sleeps all night	No
170	18	DS	He had it in the past, is a lot better after operation to remove his tonsils and adenoids to help his breathing	No
173	10	PDD	No, but sometimes he wakes up at night (by noise) and cannot sleep	Yes
179	13	PDD	Although can have difficulty falling off to sleep	Yes
181	13	ID	As he gets older he seems to be more relaxed and he also is very active physically (sport), which makes him tired and he is able to settle more easily at night	No
185	16	ID	He has got a lot better, sometimes has problems going to sleep	Yes
194	9	PDD	He sleeps very well	No
205	16	Oth ID	Restless sleeper. Easily woken during the night, but generally gets a good nights rest	Yes
208	4	Oth ID	He used to, his sleeping patterns are variable, but have improved	Yes
212	6	Oth ID	Not a sleep problem, breathing problem	Yes
223	6	ID	Doesn't like change and does like routine. It takes half an hour	Yes

to put him to sleep at night in own bed. We cannot take him
anywhere at night as he cannot sleep under any other
conditions

PDD = Pervasive Developmental Disorder

CP = Cerebral Palsy

ID = Intellectual Disability

Oth ID = Intellectual Disability due to medical condition

PDD & CP = Pervasive Developmental Disorder and Cerebral Palsy

^a Twenty parents/carers who did not perceive their child to have a sleep problem did not give a reason for their explanation.

Appendix L. Children allocated to the Unrecognised Sleep Problem Group, BEDS factors above the cut-off, parental reasons why the parent/carer doesn't think the child has a sleep problem.

Child ID	Child's Age	Child's Diagnosis	BEDS factors where child scored above the cut-off	Reason given to explain why parent/carer thinks child does/does not have a sleep problem	Does explanation indicate sleep is problematic
9	9	PDD	TOT, DYS	Not disturbed through the night other than if he gets cold, or one off	No
12	10	PDD	PARA	Goes to bed when asked with little prompting	No
17	13	PDD	APN	Sometimes I do, doesn't worry him & if you're not next to him it doesn't worry us either	Yes
97	6	ID	PARA, ESD, APN	Because apart from waking early, he sleeps like a baby	Yes
102	7	Oth ID	TOT, DYS, PARA, ESD	When she is not in pain, quite rested in the morning relaxed and happy to play	Yes
108	11	ID	TOT, DYS, PARA	Simone sleeps well, wakes up with energy and will go to bed willingly. She may sleep more than a regular 11 year old	No
124	4	ID	TOT, DYS, ESD	Sleeps well during the night, has a good nights sleep	No
126	4	PDD	PARA, ESD	Because he doesn't understand our world, doesn't understand the way things happen	Yes
146	8	ID	TOT, DYS, PARA, ESD	Because she had problems when she was younger, now sleeps at night, not a very good sleeper but better than it was	Yes

150	11	PDD	PARA, ESD	On average sleeps 10-12 hours a night, only odd night she doesn't	No
166	16	DS	ESD	Explanation not provided	-
170	18	DS	APN	He had it in the past, is a lot better after operation to remove his tonsils and adenoids to help his breathing	No
171	11	DS	APN	Explanation not provided	-
181	13	ID	TOT, DYS, PARA, ESD	As he gets older he seems to be more relaxed and he also is very active physically (sport), which makes him tired and he is able to settle more easily at night	No
185	16	ID	TOT, DYS	He has got a lot better, sometimes has problems going to sleep	Yes
190	10	PDD	TOT, DYS, PARA	Explanation not provided	-
204	7	ID	TOT, DYS	Explanation not provided	-
206	4	PDD	ESD	Explanation not provided	-
208	4	Oth ID	TOT, DYS, PARA	He used to, his sleeping patterns are variable, but have improved	Yes
212	6	Oth ID	APN	Not a sleep problem, breathing problem	Yes
223	6	ID	TOT, DYS	Doesn't like change and does like routine. It takes half an hour to put him to sleep at night in own bed. We cannot take him anywhere at night as he cannot sleep under any other conditions	Yes

Appendix M. Allocation of Parents/Carers From the No Sleep Problem Group to the Unrecognised Sleep Problem Group

Participant Number (n = 56)	BEDS Total Score Cut-off = 86.5 (✓/X)	Dyssomnias Score Cut-off = 65.5 (✓/X)	Parasomnias Score Cut-off = 25.4 (✓/X)	Expressive Sleep Disturbance Score Cut-off = 4.9 (✓/X)	Apnoea/Bruxism Score Cut-off = 1.4 (✓/X)	No Sleep Problem /Unrecognised Sleep Problem
2	32 (X)	31 (X)	1 (X)	0 (X)	0 (X)	no problem
6	12 (X)	12 (X)	0 (X)	0 (X)	0 (X)	no problem
9	90 (✓)	75 (✓)	18 (X)	1 (X)	1 (X)	unrecognised
12	82 (X)	59 (X)	26 (✓)	4 (X)	1 (X)	unrecognised
17	80 (X)	63 (X)	24 (X)	3 (X)	2 (✓)	unrecognised
18	45 (X)	30 (X)	15 (X)	0 (X)	0 (X)	no problem
20	66 (X)	54 (X)	12 (X)	0 (X)	0 (X)	no problem
21	29 (X)	25 (X)	5 (X)	0 (X)	0 (X)	no problem
22	36 (X)	25 (X)	11 (X)	0 (X)	0 (X)	no problem
32	52 (X)	42 (X)	13 (X)	0 (X)	0 (X)	no problem
44	50 (X)	37 (X)	13 (X)	2 (X)	0 (X)	no problem

55	60 (X)	45 (X)	16 (X)	0 (X)	0 (X)	no problem
58	56 (X)	37 (X)	20 (X)	1 (X)	0 (X)	no problem
78	27 (X)	11 (X)	16 (X)	0 (X)	0 (X)	no problem
87	43 (X)	35 (X)	8 (X)	0 (X)	0 (X)	no problem
97	86 (X)	55 (X)	33 (✓)	10 (✓)	2 (✓)	unrecognised
101	82 (X)	60 (X)	22 (X)	4 (X)	0 (X)	no problem
102	99 (✓)	67 (✓)	32 (✓)	8 (✓)	0 (X)	unrecognised
105	25 (X)	18 (X)	8 (X)	0 (X)	0 (X)	no problem
108	97 (✓)	70 (✓)	27 (✓)	3 (X)	0 (X)	unrecognised
109	69 (X)	52 (X)	18 (X)	0 (X)	0 (X)	no problem
113	64 (X)	51 (X)	22 (X)	0 (X)	1 (X)	no problem
124	91 (✓)	71 (✓)	20 (X)	7 (✓)	0 (X)	unrecognised
126	63 (X)	36 (X)	27 (✓)	7 (✓)	0 (X)	unrecognised
127	23 (X)	14 (X)	9 (X)	0 (X)	0 (X)	no problem
133	74 (X)	56 (X)	18 (X)	0 (X)	0 (X)	no problem
137	22 (X)	15 (X)	7 (X)	0 (X)	0 (X)	no problem
141	52 (X)	48 (X)	4 (X)	0 (X)	0 (X)	no problem
146	101 (✓)	69 (✓)	35 (✓)	14 (✓)	0 (X)	unrecognised
150	75 (X)	45 (X)	32 (✓)	6 (✓)	0 (X)	unrecognised
151	17 (X)	14 (X)	3 (X)	0 (X)	0 (X)	no problem
164	31 (X)	25 (X)	7 (X)	0 (X)	0 (X)	no problem
166	57 (X)	42 (X)	15 (X)	6 (✓)	0 (X)	unrecognised

169	34 (X)	30 (X)	4 (X)	0 (X)	0 (X)	no problem
170	63 (X)	50 (X)	18 (X)	0 (X)	5 (✓)	unrecognised
171	42 (X)	29 (X)	13 (X)	0 (X)	2 (✓)	unrecognised
172	40 (X)	34 (X)	7 (X)	0 (X)	0 (X)	no problem
173	70 (X)	61 (X)	9 (X)	0 (X)	0 (X)	no problem
179	61 (X)	42 (X)	19 (X)	0 (X)	0 (X)	no problem
181	112 (✓)	72 (✓)	42 (✓)	9 (✓)	0 (X)	unrecognised
185	97 (✓)	82 (✓)	17 (X)	3 (X)	1 (X)	unrecognised
190	122 (✓)	93 (✓)	31 (✓)	1 (X)	0 (X)	unrecognised
194	73 (X)	55 (X)	19 (X)	0 (X)	0 (X)	no problem
196	39 (X)	32 (X)	7 (X)	0 (X)	0 (X)	no problem
204	90 (✓)	67 (✓)	24 (X)	0 (X)	0 (X)	unrecognised
205	77 (X)	64 (X)	16 (X)	0 (X)	0 (X)	no problem
206	42 (X)	23 (X)	19 (X)	5 (✓)	0 (X)	unrecognised
208	94 (✓)	69 (✓)	28 (✓)	3 (X)	1 (X)	unrecognised
209	39 (X)	32 (X)	7 (X)	0 (X)	0 (X)	no problem
212	57 (X)	43 (X)	18 (X)	0 (X)	4 (✓)	unrecognised
221	41 (X)	32 (X)	11 (X)	0 (X)	1 (X)	no problem
223	89 (✓)	83 (✓)	7 (X)	0 (X)	0 (X)	unrecognised
226	40 (X)	34 (X)	6 (X)	0 (X)	0 (X)	no problem
233	50 (X)	42 (X)	9 (X)	0 (X)	0 (X)	no problem
236	65 (X)	48 (X)	19 (X)	1 (X)	1 (X)	no problem

Appendix N. Parent Sleep Diary

EVENING QUESTIONS:**DATE:****1. Were you sleepy during the day?***Please indicate with a cross on the line below.*

Very Sleepy

2. Did you sleep during the day?☐ Yes☐ No

If yes, where and when did you sleep?

Start Time

End Time

Location: _____

Location: _____

3. Did you have any medications this evening?☐ Yes☐ No

If yes: Medication: _____

Dosage: _____

Time: _____

4. What time did you turn the light out to go to sleep? _____**5. How sleepy were you at this time?***Please indicate with a cross on the line below.*

Very Sleepy

MORNING QUESTIONS:**DATE:****6. Did you have trouble falling asleep?***Please indicate with a cross on the line below.*

Much Trouble

7. What time did you fall asleep? _____**8. What time did you wake this morning? _____****9. How many hours did you sleep? _____****10. Did you wake during your sleep? ☐ Yes ☐ No**

If yes, how many times did you wake? _____

If yes, did you have trouble getting back to sleep?

Please indicate with a cross on the line below.

Much Trouble

11. How restless was your sleep last night?*Please indicate with a cross on the line below.*

Very Restless

12. Overall, how would you rate your sleep last night?*Please indicate with a cross on the line below.*

Very Poor

Other comments about sleep last night: _____

Appendix O. RMIT Human Research Ethics Committee Approval for Study 3



APPLIED SCIENCE

MEMORANDUM

FROM: Lina Papillo, Secretary, Faculty Human Research Ethics Sub-Committee
PHONE: 9925-6102
FAX: 9925-6107
E-MAIL: lina.papillo@rmit.edu.au

Faculty of Applied Science

Bundoora Campus
 PO Box 71
 Bundoora 3083
 Victoria Australia

Tel +61 3 9925 6102
 Fax +61 3 9925 6107
 E-mail
 wendy.fleming@rmit.edu.au
 http://www.rmit.edu.au

TO: Mr Anthony Robinson, Department of Psychology & Disability Studies
DATE: 17 July 2002
RE: Application for ethics approval
CC: Dr Amanda Richdale, Department of Psychology & Disability Studies; Dr John Reece, Chair, Faculty of Applied Science Human Research Ethics Sub-Committee

Your project, titled *Sleep Problems in Children with an Intellectual Disability: The Role of Child and Parent Characteristics, and Intervention Effectiveness using 'Signposts'*, has been considered by the Faculty of Applied Science Human Research Ethics Sub-Committee. You self-rated the project as Level 2 (MR; minimal risks above the everyday norm) and the Sub-Committee agreed with that rating. Some required changes to your application were brought to your attention in my memo to you of 26 June 2002. You have addressed all of the issues raised in that memo appropriately. Therefore, you may consider your project, as it is described in your revised application, **APPROVED** for a period of three years from the date on this memo.

Should your project not be completed within three years, you should apply for an extension of approval. Also, you should be aware that there is a requirement to provide a report at the end of the project. Pro-formas for both tasks are available from me.

Let me take this opportunity to wish you all the best with your research. If any issues regarding ethics arise during the running of the project, please do not hesitate to contact Dr Reece.

Sincerely

Lina Papillo
 Secretary, Faculty of Applied Science Human Research Ethics Sub-Committee

Appendix P. Plain Language Statement for Study 3

Plain Language Statement

Project Information

Sleep problems in children with an intellectual disability: The role of child and parent characteristics, and intervention effectiveness using ‘Signposts’.

Dear Parent / Carer,

My name is Anthony Robinson. I am a doctorate of psychology student at RMIT University, researching sleep problems in children with an intellectual disability. My supervisors for this research are Dr. Amanda Richdale, and Jan Matthews.

Thank you for taking an interest in this study, a sleep problem intervention for your child. Some parents are being contacted because they were involved in study two of this research, and were interested in participating in the sleep intervention.

The research involves a parent-training program called ‘Signposts’, that will be delivered in small groups (3-5) over eight weeks. Each session is two hours. There will be two groups run at different times. Group one will be run between September - October 2002. The group two program will be between October – December 2002.

To assess the sleep program, the research will also involve you completing some surveys. These surveys ask about your child's sleep and behaviour, as well as collecting information about you as a parent. They will take approximately 90 minutes to fill in. The surveys will need to be completed once before the research

starts, and twice more after that. You will also need to keep a brief daily record of your child's sleep, and of your sleep during the program.

For some parents we will also gain a measure of the child's sleep with the use of an activity monitor watch that is worn by the child to measure sleep activity.

Your participation, is welcomed, but is not compulsory. You are free to withdraw from the study at any time. Participation is voluntary and only my supervisor and I will access your data.

The results from this study may be published or presented at a seminar. A brief report of the findings from the study will be provided to you. You will not be identified in any of these reports.

If you agree to participate in the study and you have any questions, please contact my supervisor, Jan Matthews, or myself on 9925 - 7376 and leave a message.

Thank you for your time.

Anthony Robinson

(Grad. Dip. Psych)

Doctorate of Psychology Student

Dr. Amanda Richdale

(PhD)

Supervisor

Jan Matthews

(Med)

Supervisor

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745

Appendix Q. Consent Form for Study 3



PSYCHOLOGY AND
DISABILITY STUDIES

Bundoora Campus
PO Box 71
Bundoora 3083
Victoria Australia

Tel +61 3 9925 7376
Fax +61 3 9925 7303
<http://www.rmit.edu.au/departments/ps/>

HREC Form No 2b

RMIT HUMAN RESEARCH ETHICS COMMITTEE

Prescribed Consent Form For Persons Participating In Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information

FACULTY OF	Applied Science		
DEPARTMENT OF	Psychology and Disability Studies		
Name of participant:			
Project Title:	Sleep problems in children with an intellectual disability: The role of child and parent characteristics, and intervention effectiveness using 'Signposts'.		
Name(s) of investigators:	Anthony Robinson (Student Researcher)		
(1)			
(2)	Jan Matthews (Supervisor)	Phone:	9925-7376
(3)	Amanda Richdale (Supervisor)	Phone:	9925-7376

1. I have received a statement explaining the questionnaires involved in this project.

2. I consent to participate in the above project, the particulars of which - including details of the questionnaires - have been explained to me.

3. I authorise the investigator to administer the questionnaires.

4. I acknowledge that:

- (a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.
- (b) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.
- (c) The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.
- (d) The confidentiality of the information I provide will be safeguarded. However should information of a confidential nature need to be disclosed for moral, clinical or legal reasons, I will be given an opportunity to negotiate the terms of this disclosure.
- (e) The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided. Any information which will identify me will not be used.

Participant's Consent

Name:

Date:

Participant)

Participants should be given a photocopy of this consent form after it has been signed.

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 1745. Details of the complaints procedure are available from the above address.

Appendix R. Outline of Signposts Sleep Groups

Date (week beginning)	Group One	Group Two
26 th August 1	Signposts session one, and parents given sleep diaries	Parents given sleep diaries
2 nd Sept. 2	2 weeks to record baseline behaviour, and sleep diaries	Sleep diaries
9 th Sept. 3	Signposts Session two, and sleep diaries	Sleep diaries
16 th Sept. 4	Signposts Session three, and sleep diaries	Sleep diaries
23 rd Sept. 5	Signposts Session four, and sleep diaries	Sleep diaries
30 th Sept. 6	Signposts Session five, and sleep diaries	Signposts session one, and sleep diaries
7 th Oct. 7	2 weeks to record post- int behaviour, and sleep diaries	2 weeks to record baseline behaviour, and sleep diaries
14 th Oct. 8	Signposts session six, post measures, and sleep diaries	Signposts session two, and sleep diaries
21 st Oct. 9		Signposts session three, and sleep diaries
28 th Oct. 10		Signposts session four, and sleep diaries
4 th Nov. 11		Signposts session five, and sleep diaries
11 th Nov. 12		2 weeks to record post- int behaviour, and sleep diaries
18 th Nov. 13		Signposts session six post measures, and sleep diaries
April and May 2003	Signposts follow-up measures, sleep diaries	Signposts follow-up measures, and sleep diaries

